The Devastation of Lives and Lies:

Those with Lyme disease and related chronic infections respond to the Infectious Diseases Society of America's (IDSA's) request for comments.

January 4 through February 7, 2012:

2,350 Comments
490 Shares
389 Likes

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Additional Govt. Officials Concerned with Lyme Epidemic

Scott Brown (R-MA)
Susan Collins (R-ME)
Hugh Farley (NY State Senate)
Al Franken (D-MN)
Chris Harris (Texas State Senate)
Tim Holden (D-PA)
Chris Gibson (R-NY)
Kirsten Gillibrand (D-NY)
Frank Lautenberg (D-NJ)
Joseph Lieberman (I-CT)
John Reed (D-RI)

Charles E. Schumer (D-NY)
Christopher Smith (R-NJ)
Bart Stupak (D-MI)
Sheldon Whitehouse (D-RI)
Frank Wolf (R-VA)

Infectious Diseases Society of America (IDSA)
Thomas G. Slama, MD, FIDSA, Current IDSA President
Barbara Murray, MD, FIDSA, Vice President
Stanley C. Deresinski, MD, FIDSA
Stanford University

International Lyme and Associated Diseases Society (ILADS)
Leo J. Shea, III, PhD
Raphael Stricker, MD
Robert Bransfield, MD
Daniel Cameron, MD, MPH

National Institutes of Health
Francis S. Collins, MD, PhD, NIH Director

National Institute of Allergy and Infectious Diseases (NIAID):
Anthony S. Fauci, MD, NIAID Director
Carole A. Heilman, PhD, Director, Division of Microbiology and Infectious Diseases

Centers for Disease Control
Thomas R. Frieden, MD, MPH, Director, Centers for Disease Control and Prevention; Administrator, Agency for Toxic Substances and Disease Registry

America's Health Insurance Plans (AHIP)
Michael E. Abbott
George C. Halvorson

Pharmaceutical Research and Manufacturers of America (PhRMA)
Chris Viehbacher, Chairman of the PhRMA Board
John J. Castellani, President and Chief Executive Officer

As well as numerous media outlets, in the US and abroad.

* Denotes members serving on multiple committees.

Lyme Disease: The Devastation of Lives and Lies

Who? The Infectious Diseases Society of America (IDSA) posted the following question on its Facebook wall on January 4, 2012, at 12:04 pm (eastern):

What would you like to see from your society in the coming year?

Though the question was intended for the IDSA's professional membership, people stricken with Lyme disease and their loved ones here in the US and abroad took notice, seeing it as one of the few opportunities that we've ever had to make our voices heard directly to the IDSA (and the world) regarding the outdated, inaccurate and corrupt IDSA Lyme disease Diagnostic & Treatment Guidelines.

When? Those affected by the Lyme disease epidemic began posting on January 4, 2012, and the posting continues daily. We used February 7, 2012, as the cut-off date to be able to create this document and bring it to your immediate attention this month (February 2012).

Where? The IDSA's Facebook wall, which can be found at https://www.facebook.com/IDSociety

What? As of February 7, 2012, there are:
2,350 Comments
490 Shares
389 Likes

99 percent of the comments are about the devastation of Lyme disease and its co-infections and complications.

Within days we had posted over 1,000 comments, though many of us had our posts taken down by the IDSA and are now blocked from posting on its wall. Word of this unique opportunity traveled swiftly, and went viral within the Lyme disease community globally, within the first week of posting.

How? Since we saw many of our posts being removed, we set up a parallel Facebook wall to copy everyone's posts onto, and we monitored the IDSA's wall daily for several weeks, 24/7, in shifts. We then gathered up as many comments as we could to form this document (which contains very minimal editing), took up a collection for printing, and we are now bringing it directly to you.

Why? Because we need answers, we need the truth, and we need to have our lives and dignity restored. Too many lives have been devastated. Too many have needlessly died.

The despair in this document is palpable. Please help us.

Updated Guidelines for Treating Lyme Disease Should be Removed from Government Web Site Used by Doctors as Resource for Medical Protocols

Friday January 20, 2012
Contact: Dan Scandling
Joe McNulty
(202) 225-5136

OUTDATED GUIDELINES FOR TREATING LYME DISEASE
SHOULD BE REMOVED FROM GOVERNMENT WEB SITE
USED BY DOCTORS AS RESOURCE FOR MEDICAL PROTOCOLS

Washington, D.C. (January 20, 2012) – Three members of Congress who have worked to help people with Lyme disease want outdated treatment guidelines removed from a government Web site that doctors use as a resource for medical protocols.

In a letter released today to the company that manages the National Guideline Clearinghouse (NGC), Rep. Frank Wolf (R-VA), Rep. Chris Smith (R-NJ) and Rep. Chris Gibson (R-NY) said the guidelines have not been thoroughly reviewed in over five years, a condition for inclusion in the database. They urged the company to "remove the guidelines until they have been fully reviewed and revised."

"The Lyme disease guidelines of the Infectious Diseases Society of America (IDSA) have been highly controversial and have been responsible for insurance company denials of Lyme disease treatments," the congressmen wrote. "We have recently been informed that these guidelines have been re-instated on the NGC Web site, notwithstanding the fact that they are more than 5 years old and, hence, are no longer current. Our constituents are concerned that these guidelines have not been subject to a complete review for currency and that the methodology of any review has not been disclosed as required by the NGC's guidelines."

Below is the complete text of the letter:

Vivian H. Coates, MBA
Vice President, Information Services and Health Technology Assessment
ECRI Institute
5200 Butler Pike
Plymouth Meeting, PA 19462-1298, USA

Dear Ms. Coates:

As your organization is currently contracted by the U.S. Department of Health and Human Services' U.S. Agency for Healthcare Research and Quality (AHQR) to maintain the National Guidelines Clearinghouse (NGC), we write to you as representatives of areas that have a large and growing Lyme disease problem. Our constituents have again contacted us about an issue that needs immediate attention to protect their welfare.

As you no doubt know, the Lyme disease guidelines of the Infectious Diseases Society of America (IDSA) have been highly controversial and have been responsible for insurance company denials of Lyme disease treatments. We have recently been informed that these guidelines have been re-instated on the NGC Web site, notwithstanding the fact that they are more than 5 years old and, hence, are no longer current. Our

constituents are concerned that these guidelines have not been subject to a complete review for currency and that the methodology of any review has not been disclosed as required by the NGC's guidelines.
Our understanding is that the recently re-submitted guidelines are based on the July 2010 Final Report of the Lyme Disease Review Panel of the Infectious Diseases Society of America, which specifically was "not charged with updating or rewriting the 2006 Lyme disease guidelines." This aforementioned review panel was convened pursuant to an agreement between the Connecticut Attorney General and the IDSA to end the Attorney General's antitrust investigation into the IDSA's 2006 Lyme disease guidelines. The 2010 panel recommended more than 25 revisions to the guidelines, which have not been addressed. We have been presented with considerable evidence that the NGC process, which requires that guidelines be reviewed for currency and disclosure of the methodology for the process, was not complied with before reinstating the guidelines until 2015.

We urge you to follow NGC currency compliance procedure and remove the guidelines until they have been fully reviewed and revised. The mission of the NGC is "to provide physicians and other health professionals, health care providers, health plans, integrated delivery systems, purchasers, and others an accessible mechanism for obtaining objective, detailed information on clinical practice guidelines and to further their dissemination, implementation, and use." Only a careful and transparent procedure will remove the cloud that has hung over these guidelines.

Thank you for your serious consideration. We look forward to your reply.

Sincerely

Rep. Christopher Smith
Rep. Frank Wolf
Rep. Chris Gibson

OUR NATION:

On a national level, there are two bills that we urge you to support:

<u>HR 2557: To Provide For the Establishment of the Tick-Borne Diseases Advisory Committee</u>

Sponsor: Christopher Smith (R-NJ)
Co-sponsors: Tim Holden (D-PA), Bart Stupak (D-MI), Frank Wolf (R-VA)

<u>S 1381: Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2011</u>

Sponsor: Sen. Richard Blumenthal (D-CT)
Co-sponsors: Scott Brown (R-MA), Susan Collins (R-ME), Al Franken (D-MN), Kirsten Gillibrand (D-NY), Frank Lautenberg (D-NJ), Joseph Lieberman (I-CT), John Reed (D-RI), Charles Schumer (D-NY), Sheldon Whitehouse (D-RI)

OUR STATES:

On a state level, the following states have passed legislation to help allow Lyme patients to receive diagnosis and treatment:

Connecticut
Massachusetts
Minnesota
New Hampshire
New York
Rhode Island
Texas

Other states have bills that urgently need to be passed. Many more states have no legislation (proposed nor passed) whatsoever.

Todd Meese How about a cure for Lyme disease? Actually let's start with some honesty about the disease.

Joanne Drayson An honest review of the Lyme Disease Guidelines looking at the science presented at the IOM workshop and acknowledging that all is not known about this emerging complex disease with it's many co-infections.

Laurie Damsell Fahey The Five Thousand or so of us on Facebook with Chronic Lyme Disease to have treatment options.

Jaisibel Sullivan Some honesty and understanding about Lyme would be at the top of that list, thanks.

Marcella Rosenberg Less proliferation of drug resistant microorganisms.

Jacqi Euler Honesty about Lyme Disease and less restrictions on the doctors who treat patients with Chronic Lyme!

Madison Lewis Change in your stance against the existence and treatment of Chronic/Latent Lyme. Far too many people have died and are suffering severely as a result of the misinformation you've put out. Correct yourselves before you lose all respect from the Medical Community. The film/dvd 'Eyes Wide Open', opened many eyes to your links to insurance companies.. Be about True Medical Fact. This is Medicine... This is not about money and politics.

Cristopher Yulish *I would like to see all of the doctors who drafted the 2006 Lyme Guidelines exiled from the Society and barred from Medicine for conflicts of interest. They have put private and business interests ahead of the public interest. This is unforgivable.*

Redeem yourself and start fresh by helping the thousands who are suffering with a disease they can get no recognition for due to the damage from a small tyrannical group of "experts."

Train doctors to help those who are sick, educate the public with accurate information and develop some real testing methods so no one else has to suffer again.

Lori Sullivan-Mangrum Better guidelines for treatment of late stage Lyme Disease. More Lyme Literate Doctors. Doctors to have free reign to treat Lyme according to their patients, no one person has the same DNA therefore how can we all respond the same to treatment?

Lisa Calista Botto More Lyme disease awareness. It took three years to be free of my Lyme disease. This insanity needs to be addressed.

John Coughlin Explain to us why we are so sick and you can't tell us anything but make up labels and say there is no cure.. How about all those that are slipping through the cracks because of your guidelines. Docs are afraid to over diagnose Lyme so they do the exact opposite and send people home still sick! We need change too many suffering now to ignore anymore...

Kim Tarbox There is a tremendous need for IDSA to retract the degradation of an ill people and admit that your due diligence is incomplete regarding Lyme. Reevaluate the oath prior to administration of MD licensing.

Kim Tarbox Preferably before I die?

Gina Lickliter I'd like to see a reevaluation of your stance on Chronic Lyme disease....sick patients shouldn't be treated with the suspicion, resistance, and ridicule I faced when seeking treatment with one of your physicians. I think it's time for some real open-minded discussion of this topic, given the rise of tick-borne cases that HAVE been documented...How many have slipped through the cracks?

Cristopher Yulish I would like to see all of the doctors who drafted the 2006 Lyme Guidelines exiled from the Society and barred from Medicine for conflicts of interest. They have put private and business interests ahead of the public interest. This is unforgivable.

Redeem yourself and start fresh by helping the thousands who are suffering with a disease they can get no recognition for due to the damage from a small tyrannical group of "experts."

Train doctors to help those who are sick, educate the public with accurate information and develop some real testing methods so no one else has to suffer again.

Jill V. Easton Admitting that tick-borne and insect-borne diseases are in all 50 states, that it is not just an East Coast disease. I was bitten in San Diego, California, by a tick in a residential area while standing on cement and contracted Lyme, Babesia Duncani, Ehrlichia, Anaplasma, Bartonella. My elderly father was bitten four years later by a mosquito in San Diego and got Lyme and Bartonella.

I would like the IDSA to return to me my life savings of $400,000, that I have used to pay out-of-pocket medical expenses, 9 years of suffering from disseminated diseases, my successful advertising career, my athletic prowess, my health, my hope to get married, my looks, my ability to do the simple things in life that others take for granted - all because the head of Infectious Diseases at one of the largest medical centers in San Diego refused to believe that Lyme Disease exists in San Diego, even though I had seen the ticks, had an EM rash, had a CDC-positive Western Blot, was already responding to the few antibiotics I could get from another doctor, and in fact, he had seen a Lyme patient three weeks before me and dismissed her with as much ignorance and arrogance as he dismissed me.

I pray that none of you ever has to endure what we do. If you've ever had a pet, ever walk on grass, ever do gardening, ever walk anywhere, sit under a tree or are simply in the wrong place at the wrong time, each of your doctors and their family members are at risk to go through what we go through due to your guidelines.

Madison Lewis ditto on the 'Exhile from the Society and barred from Medicine' re: the drs who drafted the 2006 Lyme Guidelines!!

Bambi Albert to be given options and the right to choose how we want to be treated for CHRONIC Lyme disease.

Christy Hudson To get a diagnosis for Lyme Disease before 6 yrs, a close encounter with death and $50k+ later.

Bambi Albert We have told you enough times IDSA what we want, why don't you stop asking and do something???

Benedetta Di Lyme More research and support for diagnosing and treating Lyme disease and other related tick infections.

Diane Lyme Ballou Admit the truth about Chronic Lyme Disease and allow doctors and patients to make educated decisions on how they should be treated for this devastating disease.

Jennifer Lauren Bailey Robins acknowledgement of chronic Lyme, fulfillment of the hippocratic oath, and substantial and reasonable treatment to those suffering from chronic Lyme and its co-infections.

Naomi Rachamim An honest evaluation of the science and evidence of chronic Lyme. A look at what we as patients have been suffering for years. Cristopher, I like your comment about a new board with members who do not have conflict of interest.

Amber Gipe For some understanding and support of Chronic Lyme Disease and for us who actually suffer from Lyme disease to no longer go bankrupt in hopes of getting better!!! we need awareness and better treatments!! dont ask what society wants unless your FINALLY ready to listen and make a change!!! and p.s. let Lyme doctors treat the way they feel is necessary, if we are willing to put our lives in their hands then why try so hard to stop us/them!

Mallori Margaret educate the public! i was sick with Lyme disease & co-infections for 22 years before knowing what was wrong with me. i'm 26 now & i'm barely able to work. my quality of life is a fraction of what it should be & i'm considered more functional than most who have late stage Lyme disease. because doctors are ignorant, i turned to holistic medicine & it's saved my life! i have a long way to go but i can't help but think how much easier this would've been if education was available.. to me, my doctors, my family.

Jill Justiss I would like to see appropriate treatment for those with chronic Lyme disease and a stop to the persecution of Lyme doctors who dare to treat these patients with long term antibiotics.

Peter von Tiesenhausen To no longer marginalize those afflicted by Lyme disease and related Vector Bourne Infectious Diseases. Please throw out your existing guidelines pertaining to this now and have some that will actually help people. Those people I'm making reference to, desperately need your support.

Nicole Newell it would be great to see you acknowledge that chronic Lymes exists and let drs know it is ok to diagnose and treat ppl who have it....i cannot even get a diagnosis for it even tho i have tested positive for it three times i am told instead that i have everything else. instead of being treated i am pushed away with no treatment at all....how many years am i and others expected to suffer with this disease while you turn your back and do nothing to help.

Karie Thulon Klim Please do not delay in reforming the policy on treatment for Chronic Lyme Disease. Be sure to include all of the new and growing body of scientific research.

Tom Morton Wholeheartedly agree with Mr Yulish's comments about Lyme.

Tom Morton Speaking as a physician it is striking and sad to realize how much this issue is squelched by media outlets.....

Karie Thulon Klim I waited for years to have this scourge of an illness recognized. It's time to pay attention to the suffering, revise the guidelines, and to progressively integrate research as new information becomes available.

Jennifer Middleton I suffered for 18 years before being dx'd in May. I lost the most productive years of my life. I am only 7 months into treatment and still so very sick. It is time to admit your mistakes and become a place for healing and restoration of all of us who suffer. This is the least you should do.

Mitch Gordon Stop pretending that your guidelines are based on science and knowledgeable medical treatment. Your guidelines document is full of ignorance and deliberate lies designed to pander to the insurance and drug industries. Why is Dr. Charles Ray Jones still fighting in the courts to save his career? Why can't Dr. Eva Sapi's and the University of New Haven's Lyme research get published in a major medical journal like JAMA? Why are a month's worth of oral antibiotics still being pushed as the standard of care for a complex of diseases that such a treatment regimen doesn't even touch? Admit your dishonesty, start over, and START LISTENING.

Suzanne Ciskowski A reason to believe in you, the CDC, the government, the dr's, the people doing the tests & then the people who read the results again, a hope to help thousands of those suffer from Lyme disease & all those other invisible diseases that everybody doesn't seem to care about, a wish that I may someday be able to if not work then at least wakeup in the morning & have a day that I can even clean my home without wondering if I will be hospitalized, a dream that doesn't turn into a nightmare & be able to take a walk even just to check my mail without the possibility of fainting & then going unconscious for hours, and of course the reality that I may become a statistic & have it take me dying & an autopsy to finally discover what I had.

I've had Lyme since the late summer or early fall of 1969 when i was only 6 yrs. old from a tick bite, the tick was imbedded in my head for days before my mom actually realized it was a tick & not a scab from a bump on my head. Plus having multiple positive tests including the Elisa & western blot. And then maybe someday it doesn't take over 40 yrs. to get a Lyme disease diagnose. This was only a little over 2 yrs. ago. I've been very sick since the beginning of 1991 when all of my hopes & dreams were stolen from me. I even tried to continue my education & work until the end of 2001. I'm only 48 yrs. old & deserve a life as does the thousands that are begging for you help. Each year many Lyme suffers die & some of them don't even know they have this disease so all we ask is to be recognized & counted.

Mitch Gordon ...and my comments are based on being married to a Lyme sufferer of 8 or 10 years running...whose life has been saved and gradually improved by a Lyme literate naturopathic doctor, while everyone at our HMO who has supposedly tried to address her Lyme and babesia based on your garbage Lyme guidelines has been ineffective, ignorant and dismissive.

Ann Goldman Please retract the existing 2006 Lyme Disease guidelines which are seriously flawed. Now that Cornell University has proven that chronic Lyme disease exists please stop misinforming the public and Primary Care Physicians about vector born illnesses.

Eva Eklund It is time you start work. It could be any of you next. Any of your loved ones. And then you sure would like the knowledge of any ILADS doctor. Families infect each other, mom to child, sexually and who knows more. Borrelia and its Co-infections are worldwide. And you the IDSA is responsible for the guidelines in many countries. Being the big UNITED STATES OF AMERICA. Show it!!!

Madison Lewis If you don't change your non-medically based Guidelines, and your attacks on the few Lyme specialists, like Dr. Jones, more babies will be born with Lyme. And without Dr's like Dr. Jones, who specializes in treating infants and children with Lyme, these children won't grow-up healthy... they will grow chronic.. or die.

Debi Griffiths *Of course I would like a cure but what I would really like is acknowledgement that chronic Lyme disease "exists" and really needs treatment for longer than 30 days when it has been undiagnosed for many years and has caused damage to many body systems. Once that happens, I'd like to then be able to have practitioners who can deal with the Lyme, the toxins and the regular treatment needed just to keep us stable . . . .*

Eva Eklund Oh and what about all the people not know they are infected...giving blood...there is more than ticks that infect us. Not only do we need longer treatments and individual treatments. We need the help to get the information out. Prevention is the key and im sure you have heard it before. If you’re not going to put better guidelines out there for the many already infected. Open your eyes!!! And the people at risk!!!

Jo Brendle Yates To recognize that CHRONIC Lyme disease exists. And that it is indeed becoming an epidemic. My husband is being treated in Alabama, altho Lyme doesn't exist here....right?!?!? If he had gotten the proper treatment when his tick bite occurred, he wouldn't be in the battle for his life againt this vicious disease. What will it take to open the eyes of those in the IDSA to see how terrible this disease is?? Probably one of your own children/grandchildren, your spouse, etc......to come down with this "unexplainable" disease. One of your own to have to see countless Drs. that tell them there is nothing wrong with them, that they are crazy, that they just want attention. Is money, politics, and power more important than a person's life. Take a stand and "do what is right" !!

Yvonne Forey Try saving lives instead of ignoring dying or chronically ill people WORLD WIDE.. UK follow YOUR corrupt guidelines too but wont accept USA blood test...somethings drastically wrong on all levels...I didnt know I had Lyme, like many mothers and passed it on to my children and them to their children...In the word of my doctor " oh yes Lyme disease is a killer" then turned his back on me due to YOUR guidelines...These doctors are scared and turn people away...IF or should we say WHEN it happens to one you loved or yourself, then would you listen…probably not because you have the power and would get treated as BUSH did. Were begging you from all over the world to wake up! its beyond pandemic....allow dr's to treat without threat...just do whats in your power before its too late, already too late for many who have died of Lyme...you have blood on your hands.. HELP US

Debi Griffiths Of course I would like a cure but what I would really like is acknowledgement that chronic Lyme disease "exists" and really needs treatment for longer than 30 days when it has been undiagnosed for many years and has caused damage to many body systems. Once that happens, I'd like to then be able to have practitioners who can deal with the Lyme, the toxins and the regular treatment needed just to keep us stable.

I would love to have back my executive management career - not to mention the $1+ million dollars in salary I have lost when I couldn't work, all of the money I have spent on treatments, my athletic play time with my family, the ability to drive my car, carry on a conversation without losing the words, sleep and not feel like a prisoner in my own home. I want that for everyone who has suffered with this for, in my case 20+ years before weird health problems were finally diagnosed. I don't even care anymore if this was a bio warefare thing - all I want is acknowledgement of the disease past days, treatment, supportive therapies to help us get back to work and on with our lives. We don't like being this sick!

Dana Johnson have a heart

Kathy Obal Carlstrom I would like to see a government oversight committee put in charge to thoroughly review the dangerously misleading misinformation put out by the IDSA regarding Lyme Disease and co-infections and the curious reasons behind it, because it has become a national crisis. What is it? Conflict of interest (money)? Medical peer pressure to conform? Pride? Surely it's not ignorance anymore. People and children are literally dying and suffering and your group continues to put out to the international pubic some the most inaccurate medical information I ever seen. If you can't participate in the field of medicine honestly or use basic common sense in your guidelines, then surely it's time for those who can't to step down from their positions on the IDSA board. I do not say any of these words lightly. Change is needed. The reasons why this is happening need to be addressed now. Are there any honest people on your board? I am beginning to question this. I think a dismantling of your group is needed with fresh new people put in charge who have no conflicts of interest. This would help save lives around the world.

Lisa Hilton I would like for them to recognize that many people are suffering from "invisible" illnesses and being ignored because they chose to ignore it. I would like for someone unbiased to start researching with an open mind and find the links and causes of all these diseases and see why we aren't getting better.

Lisa Hilton *I would like for them to recognize that many people are suffering from "invisible" illnesses and being ignored because they chose to ignore it. I would like for someone unbiased to start researching with an open mind and find the links and causes of all these diseases and see why we aren't getting better.*

Leslie Boswell Farrell For them to actually put science before profit.

Tim Hart Tell the Truth about treating Lyme ! Long term Antibotics WORK !

Tracy Schittler Re-write the guidelines for Lyme Disease...stop pretending this is something that is just going to go away. We are real people..with a real disease who should be able to get real care by Doctors who dont have to be afraid to treat us the way that we need to be treated, for the amount of time we need treatment. I would also like to see some new faces on the IDSA board, ones that are willing to stand up for Lyme Disease and the people affected!! How many more have to die...shame on you!!!

Debbie Thompson First, do no more harm.

Cheryl's Lyme Page I would like to see more compassion and LESS arrogance from the members. Maybe offer classes on how to speak to patients? Use more adult terms than "vague symptoms" or "compelling stories" when we are asking you for more answers and REAL help to get better.

I spoke to an IDSA member in Bethesda MD who's only answer to me for what I could do because I'm still sick was "do you believe in God?" I said "well, yes." He said "Then maybe you should pray more" he further told me he agreed there is flaws in the guidelines but he isn't going to go against it as long as he's a member of the IDSA.

When a doctor who is a member of your dinner club states such things it's a real sign that some need to be yanked off their High Horse and get busy being a doctor.

Leonora Arnaut How about putting some people in place that will and can actually make a difference in regards to the continual denial and flawed testing and messed up guidelines that the IDSA stands so firmly behind when it comes to Lyme disease! This should NOT be about profit! How many more have to die before the IDSA admits that they've been wrong? Our medical doctors know there is a huge problem here, but are afraid of the IDSA, so their hands are tied. Your guidelines are cruel and criminal.

Gary Glaser You should do a voluntary investigation of your board using an experienced independent group that will verify that each board member is capable of participate in decision making without being influenced. Since IDSA does not report to any other organization or is responsible to document activities of the board if you wont do so the IDSA is not to be trusted and is then useless.

Liza Cammeron Toss out those painful, dated, fraudulent group of guidlines you have for Lyme patients. And stop persecuting their Drs. I don't know which around me is growing faster, more chronic Lyme sufferers, or horrifically mis-informed Doctors who remain so by believing the 2006 guidelines IDSA put out. A task force needs to dismantle the criminal group of Drs who set these guidelines, in order to line their pockets, and put out the science-based Guidelines Lyme Drs and Lyme Patients need.

Angelica Johansson Change your stance in the question of Lyme disease

Lori Ditzler Hagarman Admit that Lyme Disease is an epidemic and find a cure!

Cathy Zichichi Balsamo Work on treating Lyme disease! OK Maybe not even treat BUT Acknowledge! EDUCATE yourselves! Review guidelines and revisit!

Tony Ly Confess to the truths about Lyme Disease and start helping people so the blood on your hands will cease... Either way, there will be justice one day... God sees all things.

Gabbi Hicks Open your eyes & start supporting Lyme disease victims

Melissa Koshen IDSA DON'T YOU CARE? LYME DISEASE IS EVERYWHERE!! Start being part of the solution and stop being part of the problem.

Dawnja McCormack Realize Lyme Disease is real and everywhere and help get doctors to recognize and treat it CORRECTLY!!!

Liese Jarboe open your eyes to chronic Lyme as an infection and not a post infection syndrome. hello, if the Bb is still in the body the body is still INFECTED!!! you don't need 6 bands to be sick, only needed to report the CDC. Get your heads out of your asses and out of politics and managed care and treat people like human beings who need real medical treatment. i had a positive blood test and an IDSA provider told me i didn't have Lyme and that there is no Lyme in NC. after treatment by another doctor, i am better. you are liars and thieves!

Kat Strickland I am ten years in and proof that Chronic Lyme exists. I want to see the guidelines changed to match the standard of care we deserve and have a right to in the USA. This is still a free country and we should still have the right to select the protocol treatment options with our doctor and for how long it takes to reach a functional life style.

Gary Schittler Jr How bout new guidelines and better testing for Lyme disease !!!

Susan Lalor Help Lyme Disease Victims.

Kat Strickland In addition, I also will like for all of the doctors who drafted the 2006 Lyme Guidelines exiled from the Society and barred from Medicine for conflicts of interest. They have put private and business interests ahead of the public interest. This is outrageous and should no longer be ignored. Lyme is not going to go away. It will only increase each year. This is a plaque.
Kristi L. Servies Do something real and serious about Lyme!

Robin Sklar Fisher I would love to see drs. who believe in compassion and believing their patients when they describe symptoms instead of dismissing them. Too many people suffer from the same symptoms for it to be in the head of so many. Explain why so many of these patients improve and even get well when they obtain quality care from a llmd. Instead of attacking llmd's because their opinions differ from yours question what they are seeing and why treatments they prescribe often provide relief while you just leave patients to deteriorate. I grew up in a family with doctors and was always raised to believe they wanted to help end suffering so I question why are you allowing the untold suffering of millions? Make your New Years Resolution to be fair and honest and review your stance. Listen to the millions pleading for help!

Claire St James I'd like to see you acknowledge chronic Lyme - both its prevalence and its severity. Work WITH ILADS and other health care professionals to find solutions for this disease. If you train physicians to catch the acute cases, you'll have far fewer chronic cases to deal with in the future. Thank you!

Anne Howard Acknowledge Chronic/Late stage Lyme Disease. Please explain -If it does not exist, why are we (those of us with this illness) not allowed to donate bone marrow or blood? 37+ years with Lyme disease

Eliza Nokomis Keep your politics and your money out of my healthcare. Stop harassing mine and my children's doctors-they saved our lives, not you . Acknowledge the need for more research into Lyme and co-infections being treated in a way that helps patients not have to rely on anecdotal evidence (which works better than your guidelines since we're not waiting for you to put money into reliable research before we die). Encourage doctors to learn the clinical diagnosis criterion- not some CDC "reporting criterion" in order to identify sick patients. . educate doctors that there are more strains of Lyme and only strain has a test (therefore it is not all in our heads). Train doctors and hospitals to test for co-infections which require different medications (again, so once our "Lyme" is "cured" we don't have to lay in bed wondering why we're still sick). Educate patients that this disease is sexually transmittable and able to be passed to children in utero. Make resources available to speech and language providers, OT/PT, psych providers and schools so that our children stand a chance of making it thru one single damn day...that should be a good START for you guys.

Don't know how you people sleep at night after all the harm you have caused so many sick people. Shame on you.

Laurie Damsell Fahey All of us have the same symptoms of the Non existent disease.. in the chat rooms in the support groups.. all desperate for help.. My salivary glands are so swollen that I have been told that I probably have cancer by three separate doctors! NO LYME!! Oh well that doesn't exist we will call it something else??? I went to a hospital and got treated for an UnKNOWN Environmental Infection the poor doctor was afraid to call it for what it is?? How does that makes sense? Because The IDSA can't call it anything the hospital turned me away and perhaps I will die??? Like many others but what does it say on their death certificate? not Lyme?

Christina Gingerich *I have had Lyme for 20+ years and diagnosed 2/2011. Folks don't understand why I'm worse now than better . . . how do you explain it when they don't believe you are sick? I would like to see Drs. educated and learn to listen to their patients rather than just doing the "usual" treatment. Why are they so close-minded to this? Yes, it is a very sad situation.*

Jeannine Comtois Bennett Please acknowledge that Chronic Lyme exists. A change in the guidelines is necessary, as is educating Doctors about recognizing Lyme before it has a chance to be chronic. Too many people in the medical profession believe the drivel that was put into the guidelines. Long term antibiotics do work. I went for years and years from one Dr. to the next, one specialist to the next, until I finally found a Lyme literate MD who has been able to help me heal. It has been a long, hard road and I am not through yet. Use the Western Blot and get rid of the titer as the main test.

Nicole B. i think it is clear that Lyme policy needs to be reexamined and independent research needs to be conducted. appropriate treatment for Lyme disease and co-infections is desperately needed by the hundreds of thousands suffering from this disease!!!!

Lori Ditzler Hagarman Chronic Lyme exists! I have had it for at least 15 years and counting.

Ken Barton change the guidelines regarding Lyme'?

Ken Barton more people with HIV working in the Field! It seems that organizations have gotten away from this over the past 5 years or so!

Susan Hoover I have had Lyme Disease for 29 years; diagnosed just one year ago. I was told I could not have it because we don't have Lyme in Ohio. Really? Well, we do now. How do I "like" all the previous comments? I wish for all doctors to have to take an extended course on Lyme to get up to speed with it so they can recognize it and begin treating for it. I am a nurse and I hear patients say "I hurt all over." I immediately think "LYME!" but never, ever have I seen a patient be diagnosed with Lyme. It is a sad situation.

Ken Barton How about, More Drs with HIV on decision making boards, and.....Lyme.? This is not all about Lyme. We need to be proactive where there are failings in both of these infectious diseases.

Kimberly Anderson Elliott For IDSA members to not have severe conflicts of interest including relationships with Managed Care and Big Pharma (vaccine patents) clouding their judgment. No single organization or any Physician should make money off denying treatment to patients! "To do no harm" Remember that pledge?!?!

Christina Gingerich I have had Lyme for 20+ years and diagnosed 2/2011. Folks don't understand why I'm worse now than better . . . how do you explain it when they don't believe you are sick? I would like to see Drs. educated and learn to listen to their patients rather than just doing the "usual" treatment. Why are they so close-minded to this? Yes, it is a very sad situation.

Laurie Damsell Fahey My friend is CDC Positive lives in and was born and raised in ARIZONA yes ARIZONA the state that has the most cases of Erlichia in Dogs.. but the IDSA doctor told her its not possible there is no Lyme in Arizona.. so she tested her for HIV and then turned away. Even my Neurologist said most IDSA doctors are afraid to treat Lyme Patients and wont. The poor girl has been sick for years and has had thirteen operations.. for the same symptoms we all have.

Lauren Hentschel Lamoreaux Learn the truth about Lyme Disease and its coinfections. It can and does go chronic when untreated. And there IS hope for those of us who have it. But until YOU get it right, we have to fight tooth and nail to be treated, while being "treated" like outcasts and nut-jobs by the traditional medical community. Get the facts from people who haven't been paid off by other parties, learn what "late stage" or "chronic" Lyme sufferers go through, and CHANGE THE GUIDELINES. People are suffering needlessly here.

Elizabeth Grimm I'd like to see our society acknowledge chronic Lyme - both its prevalence and its severity. I would like for our society to acknowledge that disease and ticks don't stick to state boundaries and that every state is potentially infected with Lyme disease ticks. Work WITH ILADS and other health care professionals to find solutions for this disease. If you train physicians to catch the acute cases, you'll have far fewer chronic cases to deal with in the future. Also, please watch Under Our Skin, the documentary and consider the information it has. Thank you for allowing us to be involved!

Kim Tarbox There will come a day where you can no longer make syndromes and blame psychosomatic reasonings for lost lives. There are hundreds of thousands of walking dead...once high functioning highly educated persons ..with destructive and false labels on their charts. The continued unwillingness to address this will eventually lead to the demise of your integrity. Your current compromise will cost far more than any future monetary or scientific gain. Please ...respectfully...don't just listen ..but hear a people in great threat of our literal lives. Tell us...what will it take to aquire your commitment?

David Reinhardt Why is it that fewer than half a dozen doctors in the entire state of MI will treat Lyme and that it is almost impossible to find them? If the first four or so I went to had even considered I might have had Lyme (with history of a tic bite and bulls eye rash) 9 yrs ago, maybe I wouldn't be infected now! Are all those doctors afraid, for some reason, to get involved with Lime disease and it's politics?

Whitney Johnston Woodburn I am in agreement with everyone that late stage/chronic Lyme disease needs to be recognized. Do you realize how much patients have to spend just to be able to walk each day? We are moms, dads, husbands, wives, children etc. that are trying to contribute to society and make the world a better place but due to the lack of attention you choose to pay to Lyme disease there are many people unable to live out their dreams and use their talents. More than that people are dying because of misdiagnosis or late diagnosis. There are so many stories out there. Maybe if you took an interest in the people you are "serving" we would support you more. Why can't we work cooperatively together? What is it hurting the IDSA to acknowledge we exist?

Madison Lewis @ Whitney: The answer to your last question.. $$$$$$$$

Debbie Bates Qualls LYME disease is REAL in every state. NOW is the time to step up and take action. No need for prolonging suffering of thousands of people who all fight for their lives everyday, trying to educate themselves and others, when many of them have very little energy for anything. So many similar stories, it is hard to believe that in today’s society, there is such difficulty in making headway to get in help at all, (recognition, testing, support, research, treatment, etc)

Courtney Bailey

- quit perpetuating the myth that "Lyme disease doesn't exist" in certain states. It is everywhere!

- Quit telling all of us that chronic Lyme disease doesn't exist and that long term antibiotic treatment isn't effective or safe. It can be both if done properly. W/o that treatment I would be dead.

- Quit letting the few Lyme literate Dr's we can find be hunted down by state boards for treating us simply bc they refuse to fall in line w/ your flawed treatment guidelines! At least be honest enough to admit that your "society" doesn't know enough abt Lyme/ chronic Lyme/ co-infections to put out a set of rules (u call guidelines) to be applied across all situations. Can't we even admit that we just don't know enough abt this disease and it's various forms to establish a strict set of guidelines?

- Use all of ur profits from ur board members' patents on Lyme test/ test kits towards independent research for Lyme.

- For God's sake at least educate all students in med school that Lyme can be sexually transmitted and the signs of acute infection. We can agree that acute infection exists can't we? And that co infections exist. Here in Ohio the Dr's barely know what acute Lyme is let alone the signs of chronic infection or the various co infections! That is criminal.

- Stop teaching Dr's that all Lyme cases present with a rash! That is myth that must be dispelled!

- Work w/ independent researchers to come up w/ better diagnostic tools! To do this your board must not include members who are making ANY profit on any part of the Lyme diagnosis including tests, kits, and meds or vaccines for the treatment/prevention of Lyme.
- At the very least please use your funds to educate the ENTIRE country abt Lyme its symptoms and transmission! This is not just a coastal disease! Lastly, I will say that it makes me sick (no pun intended) that so many of us are told that our illness is in our heads. We are sick dammit! And we need effective clinical diagnosis and treatment. We are entitled to dignity and respect. Until you can admit that you have made mistakes and that there is so much we need to learn abt Lyme before we should publish guidelines (which are used like dictates directly from god), there will be hundreds of thousands of misdiagnosed, under-treated and truly ill people will continue to suffer. We refuse to be silenced! #OccupyIDSA

Susan McInnis Acknowledgement that chronic Lyme is a disease that is causing tremendous pain to hundreds of thousands of people worldwide. Acknowledgement that your guidelines for treating Lyme disease are flawed, out of date, and punishing the sickest.

Acknowledgement that those guidelines need change and the guts to actually follow through and fix them.

Chris Powell come to the table for discussion with an open mind. include ILADS docs in equal proportion to IDSA Panel members. between the two groups perhaps patients CAN be helped and the epidemic can be slowed by PROPER testing, PROPER diagnosis AND PROPER treatment....LONG term works for a lot of people including my daughter. the health risk of doing nothing = death so we choose to treat and happily sign any release necessary to get the job done!!!

Debbie Smith Let the expert doctors treat us as we need to be and help with the laws so that insurance has to pay. I've heard too many stories of people's struggles with insurance, existence of Lyme, diagnosis of Lyme, etc. If "western blot" was listed as a standard test and with a reliable lab then maybe people would get diagnosed sooner and not have to go to so many doctors, labs, MRIs, etc. In the long run it would also save insurance companies money if we didn't have to go through so much to get the answer. Thanks.

Ashley Ordecki I would like to see your guidelines changed about Lyme. This time with no conflicts of interest. Why not use Lyme literate doctors this time that are actually improving patients? It is such a shame that they are getting their licenses suspended and taken away when they are the only ones that help us. Stop hiding the truth. Someday you will have to admit it once there are too many of us to ignore. It shouldn't have to come to that. Please help stop all of the suffering. Make this a truthful year! Chronic Lyme exists! I know because I have it. I have had Lyme for 2 years before being diagnosed. 21 days of antibiotics didn't cure me and neither did waiting it out.

Alan Burdge STOP LIEING ABOUT LYME DISEASE
AND TICK BORNE ILLNESSES!
PEOPLE ARE DIEING AND YOU DO NOTHING BUT CATER TO THE
$$ SPECIAL INTEREST !!!!!!!

Alan Burdge
http://www.youtube.com/watch?v=JpPFKpFXmQ&feature=player_embedded
Dr Harold Smith's testimony
www.youtube.com
Lyme Disease is the most rapidly spreading disease, faster than HIV/Aids TB and Cancer

Alan Burdge
http://www.youtube.com/watch?v=rlwBuFAI
Joy Burdge
www.youtube.com

Alan Burdge WATCH THE TRUTH ABOVE!!!!!!!!!!!!!!!

Gary Barrett I'd like to see you take responsibility for the multiple thousands of people who have suffered because of your narrow minded view of chronic Lyme Disease. Many people have suffered due to your unreasonable, outdated and unscientific guidelines. More people commit suicide from this disease than dying from the disease itself. Why is this? It's because everywhere they go looking for medical help they can get it because of your asinine guidelines. They can't stand the pain and suffering anymore. They can't stand be mocked and not taken seriously when they go to doctors for help or end up in the ER with strange symptoms and horrible pain all over their body.
When are you going to spend more time and money searching for a cure for this evil disease rather than going after good doctors who are trying to help us and

alleviate the pain we suffer from this disease? Your policies have caused harm to millions of Lyme sufferers everywhere because your organization denies the seriousness of this disease. Why is it that in almost every state when someone goes to an infectious disease doctor they say, "we don't have Lyme disease in our state"? How can you say this to people? Get on the Lyme forums and read about people who have suffered with this disease for years and years with no relief. Your doctors say, "well, if they still suffer after taking antibiotics for a few months then they have something else wrong with them". Really? How can that be when so many people never get better?

Susan McInnis *Acknowledgement that chronic Lyme is a disease that is causing tremendous pain to hundreds of thousands of people worldwide. Acknowledgement that your guidelines for treating Lyme disease are flawed, out of date, and punishing the sickest.*

Your organization has blood on it's hands. You should be ashamed of the way you have treated those of us who have suffered with this disease. Quit playing politics with this disease and get your head out of where the sun don't shine and look at the facts, not your outdated guidelines. People are dying suffering and dying from this disease, and what are you doing about it? Helping people get better, no! You're going after good doctors and hunting them down and trying to get their licenses taken away from them. Enough of this! You are not going to get away with this much longer because we the people who suffer with this disease are FED UP! We are NOT going to tolerate this any longer. Either take us seriously and help us get better or shut down your doors.

You serve no purpose to those of us who suffer everyday with this disease. None whatsoever. I would not wish this horrible disease upon you or your family members, yet, you let me and my family suffer with this daily. I can't get treatment for it, so I have to fend for myself and self treat because almost every doctor in my state doesn't believe we even have Lyme disease, and none of the infectious disease doctors believe in chronic Lyme. So where do we go to get help? There's no where for us to go! That's why so many of us are desperate and take matters into our own hands and try to treat ourselves any way that we can.

We are sick and tired of being sick. We're sick and tired of being ignored and marginalized. It's time for you to wake up and take us seriously and start realizing that this tick borne disease is an epidemic that needs to be addressed and serious money needs to be spent investigating a cure for it. If you can't do this, then please, do us all a favor, close your doors and don't do any more harm to us. You've harmed millions of us, it's time you stop harming us and start helping us!

Ariel Marquet Please acknowledge that Lyme disease is a complex disorder usually complicated with multiple tick-borne infections.

Debbie Smith I'd like to add another comment...I hear about people being diagnosed with MS, Fibromyalgia, Chronic Pain Syndrome, Lupus, Arthritis, etc....some of these same people have also found out that Lyme Disease is the reason they have these ailments. Doctors thought I had MS....if I had continued on steroids instead of finally being diagnosed correctly with Lyme I probably would NOT be here typing this comment. Please help...this is America afterall.

Alan Burdge Association with the production of ALS in men in Lyme endemic areas.
www.actionLyme.org
Make a TLR agonist bot so we can do away with ticks-and-fungal- immune suppression.

Stephanie Michelle Kealy MY society? Obviously this society has 0 interest in me, a Lyme patient, who has seen over 30 doctors and spent thousands of dollars over the past 5 years to finally receive the correct diagnosis and treatment. In August 2011 , I began what is most likely going to be a multi-year (and thousands of dollars more) journey to recovery.

Alan Burdge IDSA LYME DOCTORS
ARE 2nd RATE AT BEST!!!!!!!!
more rd rate.
$$$$$$$$$$$$$$$$$$$$$$
is all they care about.
NOT YOUR HEALTH !!

Andrea Garner Buttram Spend the past three years in my shoes after my encounter with a tick here in GA where Lyme doesn't exist. IDSA - you will not be remembered fondly. We know and we will never, ever forget.

Kelly Tolman Curtis Wow... so many people with Lyme Disease....I have fibro and as far as I know, have never been tested for Lyme....Do they have similar symptoms....

Kaethe Mitchell *I have two children with late-stage Lyme, bartonella and babesiosis. They were never treated because we never saw an EM rash or tick. They are now, after years of illness and specialists saying they were making up their symptoms, on their way to health thanks to an amazing, non IDSA doctor. ELISAs were negative. Change your ways, IDSA!*

Kelly Tolman Curtis Also, what I would like to see is more research on fibromyalgia, and whether or not it can be traced to bacteria or viruses...I worked as an RN for 22 years, and was exposed to all manner of infectious dieases; and I know a lot of nurses who also have Fibromyalgia....

Lyme Frenz Stop turning a blind eye. This will be EPIDEMIC.

Andrea Garner Buttram Do you see the little boy in my profile pic? He's 4 years old- for the past years he's had to settle for a part time mom because there are many days when Lyme and all it's side effects win.

Ruth James @Kelly Tolman Curtis: Kelly. I've been sick for almost eleven years now, disabled for five. My initial diagnosis was ME/CFS and Fibro.

Guess what I have? LYME DISEASE.

Too bad no one would TEST me for it despite my asking for years!

Think all that society has LOST by losing US!

Kaethe Mitchell I have two children with late-stage Lyme, bartonella and babesiosis. They were never treated because we never saw an EM rash or tick. They are now, after years of illness and specialists saying they were making up their symptoms, on their way to health thanks to an amazing, non IDSA doctor. ELISAs were negative. Change your ways, IDSA!

Eva Eklund I wish i had the money to pay you more

Jenny Guzdek What everyone else said about Lyme. Try it out for yourself and prove 30 days of doxy cures the disease. Let a tick bite you, wait a few days go to see an under-educated doctor for the tick bite, take your doxy and see if you're back to normal. Oh, and if you don't get a rash let us know how you feel! In regards to Lyme acute and chronic our nation is need of serious change, you're messing with people's lives. I hope all of these messages get past the social media intern that posted this comment.

Stephanie Michelle Kealy Kelly - i believe you most likely do have Lyme. look into it asap...watching the film "Under Our Skin" should be your first stop (it's streaming on Netflix). then call your PCP and ask to be referred to a Lyme Literate MD.

Liza Cammeron An End to your corrupt Drs. You have killed people with Lyme by what you've done and haven't done. Change the board. Change the guidelines.

Lori Cotton Hobbs Families and lives are being destroyed because of ignorance about Lyme disease. If everyone at IDSA had an immediate family member with this horrid disease, the political issues would disappear. Resolve to do what you know is right regarding Lyme. Lyme is in NC!!!! My tick bite was two years before I woke up one day and couldn't walk. I have four kids to take care of and I've battled this for the past year and I'm still not well. I have to pay for most of my treatment out of pocket. Do the RIGHT thing and help people.

Ashley Ordecki Kelly, they do have similar symptoms. I was told by one dr that if my tests came back negative that it was fibromyalgia. I also had the point test done. I don't think that dr was testing for Lyme at that time either. I went to a different dr and got tests with her and came back positive for Lyme. I also know someone who had fibro for many years. She has it under control now. But, I could relate with everything! In the beginning I had mostly muscle pains and fatigue and as time went on the pain spread and symptoms kept pilling on.

Yvonne Forey Do we really think they will read our comments, we hope so but something says this post will be deleted like they delete Lyme patients...we need to copy them all and keep them...WE are our only voice we have, only WE that have suffered endless years of pain and suffering, bankruptcy, loss of lives, jobs, friends and family who dont get it...WE need to make sure we heard...something is telling me this post no matter how profound wont even get looked at, let alone taken notice of...I as well as the thousands of others hope it does and there is a change..but somehow after years of trying everything , dont think so.. lets all copy these posts and send them to who ever we think will listen..whoever that maybe.. our local news, papers etc....I pray with all my heart that we all get what we rightfully deserve, validation!

Alyssa Ryvers Adopting the www.ilads.org guidelines.

Kathleen O'Connell I agree with the above posts regarding the IDSA's denial that Chronic Lyme is killing people, ruining lives, and tearing families apart. PLEASE !!

Amanda Blaker Lyme disease awareness in CA state parks!!!!!!!!!!!!

Kelly Lehman ACKNOWLEDGE CHRONIC LYME and do something helpful about it instead of turning your backs on us and questioning are illness. we are all fighting hard. we will not be silenced. i have become debilitated over the past 15 years from being born, YES BORN, with Lyme. worse yet i have had to watch my mother deteriorate from this disease and all that comes with it. CHANGE NEEDS TO HAPPEN NOW. innocent people are suffering and dying and you, the IDSA, are doing nothing. you should be ashamed.

Jill Hess I would love to see an accurate Lyme disease test, and more research on treatment.

Pam Haisty More research on Lyme disease.

Sue Bush I have CDC Lyme positive labs. I get sick a lot. I live in SE AZ where "We don't have Lyme", despite the fact that I hail from N WI which is an endemic area.

I am forced to self-treat. I am highly educated on the topic, more so than ANY MD I have ever MET. I cannot get treatment or medications.

What I would like to see is for MD's to educate themselves and stop reading Pharma literature, and start reading sites on the Internet, they should be better at this than me.

BTW, I REFUSE TO PAY any MD that treats me like an idiot, or puts their staff or their patients or even themselves at risk do to their self-imposed ignorance. They can bill Medicare all they want, but not a dime comes off my dinner table to pay for nothing, to be treated disrespectfully, no help or even compassion.

Becky Lee To get educated about Lyme Disease, this includes the CDC & IDSA too. I never got the rash, I did however grow up covered in ticks.

Cheri Stine Published and intense interviews of all doctors registered w ILADS; admission of a lack of education and proper training in the medical schools (I saw at least 13 specialists over 15 yrs who got it all wrong - nearly killed me w meds to suppress immune system); coordination w researchers in other countries; regular surveys by Lyme patients; checks and balances; restraint on medical boards by allowing clinical diagnosis and doctor judgment on treatment; the recommendation that Lyme victims be allowed to take responsibility for their treatment; a recommendation to insurance companies to trust doctors when treating Lyme victims. I have more, but this is enough for now. Lyme has been a nightmare for my family and me, and it is in Texas too!

Sue Bush do=due

Lindsey Duval Change your guidelines to reflect SCIENCE. STOP going after doctors who are doing their jobs and stop having the ones who care have to go into hiding to effectively treat people who are suffering. Allow treatments for chronic Lyme, secondary infections, and post-Lyme syndromes/autoimmune disorders to be covered by medical insurance. Better educate the doctors who are ignorant about Lyme. Stop limiting treatment options for Lyme. Push for better diagnostic testing (IgeneX), not the silly little Western blot that is prone to false negatives.

Nina Moore Tell the truth about Lyme and that Chronic Lyme exists. I have the same story as all others suffering from Lyme, being ill for over 15 years, told I had CFS by an Infectious Disease physician, got worse and finally got the correct diagnoses of Lyme, Babesia and Bartonella. Lost my 27 year teaching career to this disease. BUT once I got the correct diagnoses and started treatment I am now getting my life back. People are suffering and dying because of incorrect IDSA guidelines and uneducated physicians. The time is now to uncover and share the truth about Lyme Disease.

Susan Hoover Interesting comment, Kim Tarbox, about being the walking dead. Years and years before I even knew what Lyme was, I called myself a walking dead person. I used to say that I was working on having a nervous breakdown. I was so tired I would fantasize about someone taking care of me. And no one understood me.

Heather Shirkey Acknowledgement that Lyme is a chronic illness ... which includes what everyone else has already mentioned regarding health care, insurance, choice of Dr, etc...

Laurie Damsell Fahey I started with a fibro diagnosis, chronic fatigue, tremors, night sweats, lost my ability to talk, face went paralyzed as the years went on took 8 years to get so severe I fell headfirst down the stairs.

Puma Of-Thenorth Adopting honest Lyme disease guidelines. Due to your present guidelines it took me years and years to get correctly diagnosed for Lyme disease and co-infections which caused me a huge loss of income, I wasted lots of money on uninformed MDs while looking for answers while suffering from horrific crippling neuro symptoms.

Lyme disease is not hard to get and easy to treat nor does two to three weeks of abx always cure it. Diseased ticks are in every state of the USA. The public and all the MDs in the USA need to be told the truth about this disease that is an epidemic and can be persistent. Vaccinations can cause harm & be toxic as well. What I want from the IDSA in 2012 is more honesty integrity and more compassion. My life would be different & much better if you had correct Lyme disease guidelines. Instead I was given unreliable testing due to your guidelines and told I did not have the disease when I did.

Cam Altee Brown 1) Education of all IDSA physicians of symptoms of Lyme starting in medical school.
2) Help stop the myth that Lyme is only in certain states. (I know a cardiologist who in fact is positive he acquired Lyme in North Florida.)

Alyson Case Please reevaluate your stance on Chronic Lyme disease. No disease should EVER be controversial, and the fact that chronic Lyme disease IS should highlight the great urgency for more research.

Jan Reber Hammett After being diagnosed with a myriad of 'floater' conditions [fibromyalgia, arthritis, carpal tunnel, cysts, etc.] in the 2+ years since a definite diagnosis of Lyme Disease, it sure would be grand to see a serious concerted focus on the long-term damage of tick-born bacteria transmission, the illnesses they cause and appropriate treatment by the conventional medicine community.

Lauren Clyde I'd also like to see society acknowledge chronic Lyme. It is true that ticks in every state are infected with Lyme disease. PLEASE Work with ILADS to find treatments for this disease. The guidelines must be changed so that insurance co's will cover the treatment of this disease as well. Not one more man, woman or child should be made to suffer because they can not afford to treat this terrible disease. The documentary Under Our Skin, told the truth about Lyme disease and this should be acknowledged. Thank you!

Ginny Passetto Many have stated this much better but bottom line is, the IDSA needs to get intensely involved with the issue of chronic Lyme and its many debilitating co-infections. How can you keep denying this disease when so many have been documented with it? BLOOD TESTS TELL THE TRUTH! I have a family member who has been sick with Lyme for 9 years now and has been more than once been tested and the bands show....Lyme and its co-infections, despite treatments received over the years. WHAT ARE YOU AFRAID OF? Doctors have been stripped of their medical licenses for trying to help people. Isn't that what medicine is supposed to be about? NOT worrying about the political controversies with insurance companies. To continue to deny there are so many with this disease, reeks of a conspiracy. You would do best to align yourselves with ILADS and other such organizations dedicated to helping people to health not helping them to their demise or debilitations!!

Christina Gallo Lyons What I'd like from my society in 2012 is for the borrelia culture test to be validated by several independent labs. Once that occurs there will be no more lying IDSA. Are you ready?? It's coming, IDSA it's coming. And what fun it will be to watch all of your doctors scrambling. Better hire a few more attorneys and PR people this year.

Laura Griffis Reynolds My 5 year old son has Lyme disease from the state of TN - where "there is no Lyme disease" - come live at my house for a week, see how he feels and what we go thru with the medicine, diet... And see if you should change your guidelines - pitiful and Shame on you!!

Melissa Antal I don't know where to begin. My husband and I and our two children were diagnosed last year. I have had Chronic Lyme Disease for at least 27 years. I went from doctor to doctor to doctor and was never even tested for Lyme. I have every symptom and when I was finally tested, I was CDC positive. If I had known before I had children, I may have been able to spare them from this debilitating disease. Now, we have to fight for treatment and we have to fight for respect and we have to fight doctors - who should know more than WE do about this disease - to convince them that there even is such a thing as Chronic OR Congenital Lyme.

How about taking our side for once? We are sick and tired and could use the support of an organization that should be dedicated to helping people like us! People are dying from this disease and thousands and thousands of people are walking around with it and have no idea! Help us...PLEASE!

Puma Of-Thenorth *Adopting honest Lyme disease guidelines. Due to your present guidelines it took me years and years to get correctly diagnosed for Lyme disease and co-infections which caused me a huge loss of income, I wasted lots of money on uninformed MDs while looking for answers while suffering from horrific crippling neuro symptoms.*

Jennifer Justiss You need to educate doctors regarding Lyme disease. We need research and we need doctors. Chronic Lyme disease is a fact. It is an epidemic. I want to know what you are going to do about it.

Yvonne Leist-creswell definitely time for IDSA to acknowledge the truth about Lyme disease and it's co-infections. Yes I was depressed as I was told I was by an IDSA member who refused to evaluate my symptoms, basing her diagnosis solely on ELISA results. Fortunately I've since found a LLMD to treat the symptoms I had when I was seen by the IDSA member. Get with the truth...there are countless of numbers of us out here suffering, some dying because of your neglect!

Margaret McCormick Preto-Rodas My daughter, now 16 , became sick just over 4 yrs ago - she was diagnosed with chronic migraines, fibromyalgia, depression and told it was all in her head. She had Lyme testing done, but her pediatrician and neurologist couldn't agree as to whether or not she was +...how can 2 drs read a test result so differently? These past 4 yrs have been hell for her. She has some bright spots, but few and far between.

In May of 2011 she woke up PARALYZED from the hips down. We took her to the ER where they were concerned until we told them she was being treated for Lyme disease. As soon as they heard that, they sent a psychiatrist to talk to her (and to us). After being sent home while she was STILL paralyzed (and with NO assistance) our pedi recommended Boston Children's Hospital - they too were nice until they heard she was receiving IV antibiotics for Lyme - once they heard that, they too sent the psychiatrist to talk to her (and again to us). They told us she had conversion disorder - in other words she was subconsciously making her legs not work so she could avoid doing something she didn't want to.....mind you, she is on homebound as her brain fog, concentration, body pain and fatigue are too much for her to attend school, she doesn't participate in any extracurricular activities and rarely goes out. Just what was she trying to avoid?

And how can any dr in their right mind send a paralyzed person home with no assistance? Thankfully we had a portable toilet, wheelchair, walker, etc left from when my mom was ill. We have little trust left in the medical community - and our daughter, has none left. She recently had horrible acid reflux - the pain from it was unbearable - she refused to go to the ER because she knows they will do little to nothing for her. My husband and I finally called 911 again, the EMT's were very helpful until they heard she was being treated for Lyme. Once they heard that, they decided that she was having an anxiety attack and took their time getting us to the ER. Thankfully an ER dr listened to her symptoms - he ruled out a blood clot (due to her PICC line) and then tried treating her for acid reflux.

The medical community and IDSA MUST WAKE UP and realize that Lyme is a SERIOUS, CHRONIC (for some, not all) illness! New treatment guidelines need to be established, funding for research made available. The Lyme community is TIRED of being told they have other illnessess or being denied treatment! Chronic Lyme is REAL - if you don't believe me, feel free to come visit with my daughter. She will change your mind. WAKE UP IDSA and help all who suffer from this awful, tricky, chronic form of Lyme.

Gina Magee Because of your self-interests and closed-minds, IDSA, you are blatantly ruining many people's lives, and that includes caring doctors who try to treat people with Lyme. What are you afraid of that you treat people this way? There is no disgrace in updating your research, guidelines, etc... But there is disgrace in holding fast to outdated ways of thinking. And, not only that, you are perpetuating these fallacies about Lyme disease at the expense of many others. What happened to "first do no harm?"

If you want to do anything, why don't you update your guidelines, educate medical students and doctors, and stop going after good docs. You are not only keeping people sick, but you are creating lives for them that are becoming unbearable - physically, mentally, spiritually, financially - and the list goes on. It would be my wish that the members of the IDSAespecially the perpetuators of the Lyme guidelines, be held accountable and be made to pay damages to those affected by your actions (because they seem criminal to me). I wish I could understand your motives. Why are you making so many people suffer?

Amy Topper Watkins *Acknowledgement that chronic Lyme exists. There are so many people suffering and being treated like they are crazy because you refuse to acknowledge its existence. Think about something other than your pocketbooks. Look at the faces of the sick, my 8 year old son being one of them, and do something to help them.*

McRae Harriss Lyme disease truth/help!

Margaret McCormick Preto-Rodas One final comment - YOU, IDSA, hold the health and well being of my daughter and thousands of others in your hands - Do NOT fail them, pls!

Billiejo Miller Rush ADMIT Late stage/chronic Lyme disease needs to be recognized!! and your testing is an EPIC FAIL!!!

Liza Cammeron Under Our Skin Good Morning America National Coverage
www.youtube.com
National news coverage on ABC's Good Morning America on award-winning Lyme Disease documentary. This film chronicles the controversy and debates surrounding ...

Alan Robison An ID doctor gave me a Western Blot after I demanded that he include it in the battery of tests he offered. It was the only test that came back positive: To his dismay and disbelief, CDC positive! Even then, he refused to acknowledge the obvious because I didn't present a rash or joint pain. After years of being told I needed psychiatric help, I thanked him and found a more progressive physician.

JC Hoskins for the ISDA to acknowledge that many people are getting sick from tick bites. People are sick and dying because the organizations designed to help patients are not. Educate.

Kd Lyme Honest, accurate and unbiased research of Lyme disease that's not intended for the sole purpose of proving yourselves right. Charges of crimes against humanity for Wormser et al would be nice as well.

Joni Boyd Please figure out the chronic or late stage Lyme is a REAL illness hurting REAL people--taking away their lives, money and robbing them of their health and faith in doctors. I am a nurse--and I have watched my cheerleader daughter go from an A/B student in highschool to having to withdraw from school--missing her prom, homecoming, friends, EVERYTHING!!!!! We are spending our life savings trying desperately to get her well!!! IDSA--GET A DOSE OF REALITY!!!!!

Thane Lyme I would like to see you come clean about your cover-up of Chronic Lyme Disease.

Tracy Hans Yes, I would cheer to the high heaven if the IDSA took an honest, clear look at how many folks are truly suffering from infectious tick borne illnesses and start to educate IDSA docs appropriately. An honest revision of the guidelines that looks at ALL reputable literature out there, would preserve the health of millions.

Thane Lyme I would like to see you at least have the courage to not delete this thread.

Cecelia Cece Price Jones Greater listening & backing of those members of society that are afflicted with Lyme disease &/ or co-infections & the docs who treat them & bring them back to health!

J David Kocurek To recover public trust, the society must develop guidelines for and enforce intellectual honesty in all publications, communications and any other endeavors - or more simply, be true to the science.

Amy Topper Watkins Acknowledgement that chronic Lyme exists. There are so many people suffering and being treated like they are crazy because you refuse to acknowledge its existence. Think about something other than your pocketbooks. Look at the faces of the sick, my 8 year old son being one of them, and do something to help them.

William Jones Hopefully Ron Paul will do away with them if he is elected :)

Monica Zmuda I have had Lyme disease for over 4 years, multiple treatments. Positive Blot and co-infections. Recognize Lyme disease in the chronic form. I was a nurse for over 15 years, I now can not practice due to Lyme Disease. I think a HUGE lawsuit should be brought up against IDSA and the money be returned to all of us, plus more for the suffering!!! I pray your family never gets afflicted with LYME! Only then will you truly understand. Would you risk your life and test the theory? There are unlimited amounts of infected ticks in every state waiting for the opportunity!!!!

Jessica Gontarz-Durfee I want someone to acknowledge chronic Lyme, for my nine year old son's sake.

Josh Cutler I would love nothing more than to see a non biased review of the guidelines for Lyme disease. I would also like to see proof and evidence based research again PROVING that Chronic Late stage Lyme disease does not exist.

Clearly so many people are suffering. Look at this!! Is this in THIS MANY PEOPLES HEADS? I don't think so. Most of us have lost our careers, lives, homes, family and some have even lost lives. All because of what? We are not here to cause issues. We just want fair and just treatment. This will NOT stop till we have proper treatment and research for a cure.

Show us PROOF PROOF PROOF from unbiased researchers that we are making this up. Are you really going to sweep thousands of people under the rug to die.

What if this was someone in your family fighting for their life?

Vanessa Baker-Simon I would love to see more sensitive and accurate testing for co-infections carried by ticks.

Charlie Henry-Bladorn Please, please, please revisit Chronic Lyme. Too many are suffering and crying for help. We don't want to be sick, we WANT to be better. With an early diagnosis the treatment is fairly basic and not cost prohibitive at all. Instead there is so much ignorance and denial that this has turned into an epidemic with uncounted frustrated sufferers.

Thane Lyme Lyme Disease has destroyed my life. It's time you put the interests of the world's society ahead of your own corrupted IDSA Society.

Angel Williams Spell haha......and it would be great to get a response after asking this question...c'mon tell us what u think about our responses

Shawn Watkins I would like to see an acknowledgement of Chronic Lyme Disease and the effectiveness of long term antibiotics in fighting it by your society.

Kristin Martin Do something about Lyme. People are losing their lives and living in misery because of it and it's completely unnecessary.

Josh Cutler Guys, based off previous threads/comments being deleted. I would suggest taking a screen shot for yourself so that we can share all of this in case it does get deleted.

Todd Meese 177+ comments in 10 hours. Are you "Drs" listening? WE AREN'T GOING AWAY! WE WILL NOT SIT QUIETLY.

Lisa Hilton I would like to see all these "invisible" illnesses taken serious. We have a country here of sick people and ignoring us is inhumane. We need research and we need it done by unbiased people who don't already have their mind made up that we are all just crazy. Children are sick, people are dying, many of us are completely disabled at very young ages! It's time to admit that there is an epidemic and put egos or past learned concepts aside and start healing people.

Jennifer Bays Toombs Stop damning people to a life of pain and disability. Start becoming a part of the Lyme disease solution, instead of the problem.

Lisa Hilton Also I think it's time to get rid of tests that don't work. If they are inaccurate then it should be a crime to use them. Many drs have no idea how inaccurate these Lyme tests ALL are, and they tell you you dont have Lyme based on them. The CDC even states that they are not to be used for diagnosis but thats what drs do, because you encourage it for insurance reasons. Not fair to patients. Start working for the patient again and not the insurance companies.

Tina Spock-Kopcik The Hippocratic Oath that you have taken should not be ignored. There are too many of us who are not "mentally" ill, but physically ill from a bacteria that you downplay and turn a blind eye. How many others have to suffer from this plague that is continually silenced??

I want the last 4 years of my life back, before this nightmare, when I was healthy and strong. Not now where I still face doctors who say, "it can't be Lyme and it is most certainly not MS." Ok then, what is causing my brain lesions and problems with my nervous system. My MRI's and blood tests tell the story for which you choose to ignore.

Thanks IDSA for making a laughing stock out of those who have been unfortunate enough to have been bitten by a tick. By the way, tell your IDSA buddies to get there story straight when talking to patients. I know it's really hard for you to fathom that a deer might stray from Massachusetts into Connecticut with an infected tick on it. How about starting from scratch and test for all Lyme bands? I believe that would be a great place to start. If that is not sufficient, let's get going on a better test. Our children deserve better than to be disabled by a bacteria such as Lyme.

Kevin S Thomas I was treaded by an Infectious disease specialist when I was st diagnosed with Lyme.. She stated that there is no such thing as Chronic Lyme and that since I had a months worth of IV antbiotics I was cured. I didn't know any better.. Two months later I relapsed and am now sicker then I was in the st place! The Lyme treament guidelines need to be changed!

Andi Merna Mccormick Admit chronic Lyme exists and 4 weeks of antibiotics are NOT enough!

Courtney Lynn Lyme disease has ruined my life thus far at only 26 years of age. I went undiagnosed for years and suffered needlessly due to the improper testing and ignorance of so many doctors. I think you already know what it is that we all want. Its time you all step up to the plate and do the right thing. We need proper studies done for effective treatment of this disease.

Sara Stegner Lehner the truth about Lyme disease, chronic Lyme, and co-infections. I really do not enjoy writing a check out to my health insurance company every month and not having a doctor in my "network" admit there is chronic Lyme. Aside from living a lower quality of life, we're going broke.

Jeanne Bain I agree with Lisa Hilton. Take these invisible illnesses seriously. Lyme, Bartonella, PANDAS, etc. need to have money spent on research for all of them. Congenital infections need to be explored and not discounted. When my son was hospitalized for suspected Bartonella, the ID docs didn't even bother to test him. Nor did they explore the idea that my son's illness is congenital (which it is). They screwed him. SCREWED him by treating him for 24 hours and sending him home.

SubLyme Contender WAY TO GO LYMIES......who said we didn’t have a voice.......hey i dare u to ask us another question...i have truly gotten tickled...and loving it..........

Michelle De Libero Ordecki What I would like to see from you is for you to wake up and stop being so stupid about CHRONIC LYME DISEASE. Twenty one days of antibiotics is ridiculous. Get your act together.

Sherri Elsworth You need more pediatric specialist doctors that our Lyme Literate. Better yet let the Lyme specialist do their job!! Let the family's have insurance that can be used to pay Lyme specialist for treatment. Not having family's have to move in with there parents or getting a second or third job just to pay for the on going cost of treatment. I agree a disease should NEVER be controversial. You asked so you got truth from all the people who have to suffer your inadequate testing process!!!

Jordana Pilmanis Please acknowledge the existence of chronic Lyme and the damage it is doing to people's lives, the amazing suffering it is inflicting. Please have IMPARTIAL doctors review the science between both IDSA and ILADS standards of care - not just what the docs with a monetary interest in IDSA recommended test kits and pharma/insurance company kick backs say is "science." Lyme disease is spreading and is being misdiagnosed. People and insurance companies are paying thousands of dollars for care for mis-diagnosed diseases. Just because treatment takes a while doesn't mean it is not the right treatment.

Please also look at the Lyme infection statistics in canines in Colorado -- and find out what vector is infecting the dogs, because it's infecting the people, too! Please educate doctors throughout the country that Lyme is no longer geographically limited. Please educate doctors everywhere that Lyme needs to be treated because over the long term, it is degenerative and progressive. Why are you dooming so many to so much suffering by recommending two tiered testing that returns so many false positives? We need better tests! We need to have acknowledgement that Lyme & co-infections require long term treatment!

Jennifer Schoonmaker I have an infection that is very difficult to treat and has taken over a year to find, first presented as Q-fever. I am not paranoid, am well educated and do not wish to be in a Lyme war, I cannot begin to tell you how I have been treated by the majority of the twenty doctors I had to sift through to find someone to run the correct testing. I have lost almost everything of fiscal value in my life, there needs to be some revision of these Lyme guidelines and the spread of information needs to be more efficient.

Shannon Devine I would like to see doctors allowed to treat their patients without interference from those with different opinions. I would like to see common sense. Anyone with Lyme: please try Liquid Samento. Only thing that has worked for me and my teenager. I get no kick-backs, only the hope that at least 1 person will be helped. Google it and find a dose schedule (1 drop to start). You all are as strong as warriors and anyone promoting IDSA's stance on chronic Lyme should be ashamed of themselves.

Stefanie Manning Reconsider your guidelines for testing and treatment of Lyme Disease. I nearly lost my life based on your flawed positioning. 2 weeks of antibiotic, then relapse. 30 days...relapse. 14 hospitalizations, 3 ICU stays...doctors saw my Lyme rashes/bullseye and were scared to death to treat me, so they'd throw me to the next doctor and "specialist" until a doctor knew my rash and symptoms were Lyme related, had positive blood results after months of false negative tests, and saved my life with long term antibiotics.

Almost $800,000 later, I finally have a somewhat normal life back, with pain, weakness and other lasting symptoms that made this 29 year old cheerleader and dancer as incapacitated as an 80 year old at age 26. This could all have been avoided if your guidelines supported the THOUSANDS of suffers, scientists, and doctors that have been sharing their experiences and scientific data collected. Open your eyes and ears and realize people are dying on your watch and gravely suffering...ACT NOW...please...

Stefanie Manning *Reconsider your guidelines for testing and treatment of Lyme Disease. I nearly lost my life based on your flawed positioning. . . .*

Almost $800,000 later, I finally have a somewhat normal life back, with pain, weakness and other lasting symptoms that made this 29 year old cheerleader and dancer as incapacitated as an 80 year old at age 26. This could all have been avoided if your guidelines supported the THOUSANDS of suffers, scientists, and doctors that have been sharing their experiences and scientific data collected. Open your eyes and ears and realize people are dying on your watch and gravely suffering...ACT NOW...please...

Jordana Pilmanis ** Sorry, I meant false NEGATIVES, not positives. The testing returns false NEGATIVES.

Shannon Devine LLMDs and others risking their license and reputations and anything else to treat us, you are the heroes.

Stephanie Spicer Please acknowledge the existence of chronic Lyme disease and make it less than impossible for us to get the medical help we need. Provide protection for doctors who help us. Change outdated laws. Admit error.

Randi Beth Einzig I was just looking in the mirror today feeling like I was having a seizure! I said out loud I cant believe I havent killed myself-I have had an electrical headache for 5 years! I have had a headache for almost 2,0000days! I have been infected with Lyme for 10 years and found out last year after seeing 38 Doctors and an expenditure of $110,000.

I have paid over half of that and was a single mother just starting my life. My daughter used to sit in her first grade classroom and fear that I would die because I could not stand up anymore or get her to the front door of her school. I was one of the top gymnasts in the state of Wisconsin and competed at the National level. I used to run marathons. I am a mental health professional and ended up crawling on my office floor with my clients because my BP was so low!

It is criminal that I live in the United States and have had to experience this kind of agony and torture. If I were a dog I would be have been diagnosed and well long ago. My wish is that you would be honest with yourselves about the needs of human beings that are ill. Look at the facts. There are hundreds of thousands of us in searing pain-Many are children-Look at your child tonight and imagine if something so violent as Lyme took your childs health from them-Look at my beautiful baby in the picture. I took 14 antibiotics a day to safeguard him from Lyme, Babesia, and Bartonella. Praise god he is healthy!! Time to wake up and start caring about people! Life is about more than adhering to dated guidelines to grease your plate...Where are your Ethics? Without ethics, you have nothing!

Amber Hodge Aker Please recognize these illnesses so these patients can get the treatments they need and deserve. I have two friends who suffer from Lyme Disease and they travel across the US trying to find doctors who can and will treat them.

Julie Howard Seems a bit absurd to see this question posed by IDSA and perhaps even more absurd that I would bother commenting...but sitting idly by wouldn't be right, either, so...IDSA, thank you for asking. Please acknowledge the suffering of people with chronic Lyme infections. Please ackowledge the improvements and remission of many due to very expensive and extensive treatment by only a handful of compassionate physicians who are willing to take a chance. May you never have to experience first hand the pain and suffering of this very real disease.

Tish Healy I'd like to see you admit the TRUTH about chronic and recurring Lyme disease. Why don't you try working with the Lyme literate physicians to help people instead of denying that so many are sick. We've lost jobs, homes, marriages, relationships from this nasty disease. Don't tell us it doesn't exist. We live it every day!!!

Kelly Mairson To stop denying that chronic Lyme exists & look for a cure to help the millions of people suffering with this. Include ILADS guidelines in your recommendations & suggest doctors go through the ILADS training program so they can properly treat their patients.

Debi Collins Please diagnose and treat me and my family exactly like you would diagnose and treat a member of your own family.

Stephanie Spicer We are too many for you to push this thing under the carpet anymore.

Deb Labarbera Chronic Lyme Disease DOES exist whether you want to admit it or not. I am living and dying proof. How can you be so closed minded NOT to educate yourselves further to help those who need to be diagnosed and treated properly? Children are dying. Young adults are dying. Adults are dying all because of you brushing our illness off as something that does not exist.

If you had someone in your family, a loved one, a friend or if YOU, yourself suffered from this disease I am confident you would look at this in a completely differently light. Turn your BRIGHT lights on and open your eyes and minds!!!! This is one of the fastest growing diseases that is debilitating lives and taking lives away. You should be ashamed of your actions. I was treated in 2004 for 6 weeks by an Infectious Disease Doctor who ended my treatment stated I was experiencing residual effects of Lyme disease. Over the years, I became increasingly ill, seeing countless specialists and spending thousands of dollars. All the 'specialists' did was 'band aide my pain and illness...coming up with 'other' diagnoses, but NEVER considering it was still Lyme in my system even though I told every doctor my suspicion that it was.

Now.... in late stage chronic Lyme disease that was PROPERLY diagnosed, I have no chance of being cured-only possibly remission. I am only 48 years old. Look at what YOUR ridiculous decisions have done to us... Just look. Open your eyes and minds. Think of others. Think outside the box a bit. EDUCATE YOURSELF!

Karie Thulon Klim For years on end I was reassured my symptoms were "nothing." If now we know nothing means Lyme, then nothing is something and "nothing" truly could be included on the medical diagnostic decision tree. Nothing now has new meaning of chronic and late- stage significance. Everyone needs to know what nothing really means and get proper respect, attention, and treatment for it.

Tish Healy A response would also be welcomed!

Kim Finch Sick for years & Drs. testing for many things BUT Lyme. Once chronically ill, I had gotten Bells Palsy and tested positive for Lyme. On and off antibiotics for many years, it was too late & stole my life away. Many of us don't have the $ to go above and beyond what the insurance companies won't pay for. We need research & results that will help us! Please reconsider your guidelines for treatment!

Tish Healy Hey, I'm curious. When is "World Lyme Day"??

SubLyme Contender haha tish thats what im screaming.....a response would be nice.

Stephanie Vandagriff To redo the guidelines on Lyme Disease! Stop being closed minded and self serving and help our Lyme community!

SubLyme Contender they could start by saying they were sorry for being more interested in money than the people the swore to protect...and then they could "get on the common sense wagon" with the rest of us....its not that hard.....its kinda hard to believe that we r the crazy ones...i don’t know how they sleep at night...i would be ashamed of myself

Linda Erickson I am appalled at the level of misery, physical, emotional, and spiritual, that some doctors will say "it' all in your head". Where is your compassion? My fervent wish is that all doctors would listen to and trust their patients, and would become educated about chronic Lyme. Open your minds and your hearts, PLEASE!!!

SubLyme Contender and it sounds to me they have been infected since they cant retain any new knowledge....*current research*

Benjamin Mahoney I am a 28 year old male who has lost everything and lives on disability because of your "guidelines" on Lyme Disease. I would like to see YOUR society admit the truth about Lyme Disease.

Alyssa Knapp The IDSA must revisit its Lyme disease guidelines. Chronic Lyme / Persistent Lyme / Late Stage Lyme...whatever you choose to call it is very real and it exists. It is time to start treating people who are very ill with a very real disease. Long term treatment works....I am living, walking proof. It has taken 4 1/2 years of consistent treatment but I am living my life again. I beg of you...for all the people I know and love who are now suffering....please, change your treatment guidelines, find better testing and start treating everyone with the respect, kindness and dignity they deserve.

Lysandra Cook I would like you to revisit your stand on Lyme disease. My life was changed for the better when my doctor followed the ILADS guidelines rather than yours. It took me 5 years and countless doctors to go from being nearly disabled and on many medications to living my life again.

Wendy Vogt IDSA should stand for more than I Don't See Anything. You are currently responsible for an unchecked epidemic in the US... do the right thing and start being what your name stands for - be the experts on a disease that is growing faster than AIDS. Start now.

SubLyme Contender does anyone got this saved in case they delete it?

Kim DeSantis Goodwin Our lives are being taken from us this illness is a living nightmare. 10 drs and told MS, fibromyalgia, depression, pain management and the list goes on. Gave it to my daughter during pregnancy. I was symptom free for two years no bulls eye rash and slow onset of symptoms. There are so many symptoms that are not even mentioned, co-infections not mentioned. Healthcare not covered, Lyme drs losing their license when they save lives…. people are dying or wanting to die from this, losing all their money trying to find out what’s wrong and no coverage.

What is happening is criminal and our lives are being robbed and so many people know the truth and hide it. Fda has enough money please don’t ruin lives for money. We need funding for a cure, knowledge for people who are still undiagnosed walking around thinking they have something they do not have. The public needs the truth, drs need the truth and we deserve it just like if someone has cancer they get treatment. One month of antibiotics is a cure for chronic Lyme you have got to be kidding me.

If you had chronic Lyme and went through this hell you would see how foolish and ignorant that is and make you wonder what secrets are being kept. The people in charge of these guidelines have on their shoulders deaths, broken families, lost homes and unemployment, millions lost quality of life, kids losing their parents as an active part of their life forever changing families. I'm so angry i lost 6 years of my life being sick every single day. Try having the flu for 6 years everyday and want to keep living. Some have lived with this a lifetime. Our Lyme drs are saving our lives and they have a warm place in heaven waiting for them someday for saving us. educate and its all proven. Help don't kill.

Debbie Ray *You all need to drop your stance on Lyme Disease and all the silly politics involved. I have suffered for 10 years and my Infectious Disease doctor won't treat me with IV antibiotics. I continue to be sick and no one seems to care that I can't take care of myself or my son all because of this horrible disease you say doesn't exist!!! SHAME ON THE IDSA!!!!!*

Lucretia Perilli Please admit that members of your nonprofit organization falsified information about accurate testing for Lyme disease in order to falsify the Lyme vaccine trials outcome (which was a complete fiasco). This happened yrs ago, causing a massive domino effect – you put out falsified information, brainwashed the medical community into believing it, and so on. And now, millions have been misdiagnosed, never diagnosed, never given adequate treatments, never told the truth. Millions are severely ill and many have died. Endless, needless suffering – all due to the extremely questionable decisions that were and are made by your professional nonprofit organization.

Please finally admit that late-stage Lyme disease exists, is far more complex than a swollen knee/achy joint disease (and is NOT post-Lyme syndrome), involves virtually every bodily system including the brain and CNS, and consists of related bacterial, viral, fungal, mycoplasmal, prion, etc, infections, which are severely incapacitating and working in conjunction with one another -- synergistically. You could call it HIV-negative AIDS, which you know it is.

Do you realize just how many lives, including mine, that you have permanently RUINED? Think about that. How can you people sleep at night? Oh, that's right. I guess that you cannot be wounded when you've got no heart.

Hallie Richwine @subLyme contender - screenshots of all comments until mine right this second.

Laura DeCoste
just PLEASE...please help us.

Cathy Tutty I would love to see IDSA really examine autoimmune and tick-borne disease connections. I would love even more if you would look for some protocols and endorse some treatment for those suffering from these insidious diseases!

Stephanie Vandagriff Good job Hallie!

Stephanie Vandagriff We should send this link to all news stations to gain national attention.

Chris Kasper I would like for the idsa to stop trying to sweep Lyme disease under the carpet. There is too much suffering.

Lisa Hilton I would also like to see someone study the connections between all these new mysterious illnesses that are popping up. Is there any studies being done to see what causes fibro, chronic fatigue, ms, parkinsons, alzheimers, lupus? Since none of these have a causative factor, could the connections be borrelia?

Cory Boyd My sister's been sick with Lyme disease for over a year, and it's ruining her life and hurting my family. I would love to see actual recognition of chronic Lyme disease and an actual treatment.

Debbie Ray You all need to drop your stance on Lyme Disease and all the silly politics involved. I have suffered for 10 years and my Infectious Disease doctor won't treat me with IV antibiotics. I continue to be sick and no one seems to care that I can't take care of myself or my son all because of this horrible disease you say doesn't exist!!! SHAME ON THE IDSA!!!!!

Lisa Hilton "All truths are easy to understand once they are discovered; the point is to discover them." ~Galileo
Ashley Ordecki Yeah, SubLyme. I screen shot it all!

Madison Lewis @ Tish: women posted 'Lyme Month' on this site. The post was deleted, and the 2 women were no longer able to comment on this page. Does this not speak a world of volumes about the lack of integrity and the degrees this 'Society of Drs' will go to in order to squelch the very existence or advocating the existence of Chronic Lyme or any opposition to their lucrative 'Guidelines'.

Donna Harris Pruitt Lyme disease is no longer about science or sick people. It is about money, power and greed. Yours, big pharmas, insurance companies. I want to see you live up to the Hippocratic Oath you all took when you became doctors, and stop worrying about lining your pockets. Acknowledge Lyme Disease in all of its fforms, instead of ignoring the science that is in front of your eyes, and if you are unwilling to treat us, let the few doctors who are willing to treat us, to do their jobs na d stop persecuting them, and ultimately killing us. And if you can't do that, I really believe that the IDSA should be abolished, as should most, if not all, state medical societies, until they are willing to go back to science and patients' best interests. Though this post will probably be deleted, at least I have gotten a brief chancew to speak my peace. Do the right thing!

Lucretia Perilli *Please admit that members of your nonprofit organization falsified information about accurate testing for Lyme disease in order to falsify the Lyme vaccine trials outcome (which was a complete fiasco). This happened yrs ago, causing a massive domino effect – you put out falsified information, brainwashed the medical community into believing it, and so on. And now, millions have been misdiagnosed, never diagnosed, never given adequate treatments, never told the truth. Millions are severely ill and many have died. Endless, needless suffering – all due to the extremely questionable decisions that were and are made by your professional nonprofit organization . . . .*

. . . . Do you realize just how many lives, including mine, that you have permanently RUINED? Think about that. How can you people sleep at night? Oh, that's right. I guess that you cannot be wounded when you've got no heart.

Robin Gunn I would like the IDSA to set aside egos, politics, conflicts of interest and do the right thing. Throw out the 2006 Lyme guidelines. Get a new panel of doctors- doctors that treat Lyme disease and rewrite proper, ethical guidelines based on reality. The needless suffering caused by the ignorance of infectious disease doctors is unbelievable.

Stephanie Kodakya Phillips its about time you get real about Lyme.

Lisa Hilton What about more studies on how it is transmitted since almost no one even remembers a tick. What about sexual transmission? Blood transfusions? childbirth which we already know but drs don't seem to? Other insects?

Elaine Facteau Walker How could someone possibly think that these infections can be easy to treat? I'm sure you understand it but you need to ACKNOWLEDGE the fact that this issue has gotten very messed up and it is hurting thousands of people. Stand up and make some changes for the diagnosis and treatment of tick borne diseases. Be able to look at yourselves in the mirror.

Stephanie Vandagriff I contacted cnn and sent a link to this. Everybody, send a link to other news stations! We need to get stations to cover this!

Lisa Hilton to Ann-Marie O'Shaughnessy, you could include this in your project to Anderson Cooper.

Gail Sheffer Please re-work the latest guidelines and quit cherry picking the medical literature that backs up your old outdated guidelines. I am not here to bash IDSA, but man oh days, your guidelines are NOT WORKING !!! What would you do if your children or spouses got sick with Lyme or some other tick borne disease and every time you stopped treating them with antibiotics they got sick again?? You would try it again and treat them longer wouldn't you? YES OF COURSE....you would. And they would get better, as many of us have!!!!

Shar Christensen The IDSA must revise its Lyme disease guidelines. Chronic Lyme / Persistent Lyme / Late Stage Lyme...whatever you choose to call it is very real. It is time to start treating people who are very ill with a very real disease. Long term treatment works. There are thousands of Lyme patients who would like to share their story. They have more knowledge about this disease than IDSA can imagine because of necessity. Find the cause, find the carriers, find a cure. Please.

Yvonne Forey I would like to stop being confused and sleepless.... AM in the UK and would love you to just try one month of just one tiny symptom of Lyme disease..Insomnia! but maybe you do and that's why you IDSA cant figure out what the hell is going on.. like most of us cant..but thank you for you question, at least its given me here in the UK something to do while worrying how I am going to help all my children and grandchildren who now suffer because I didn't know I had Lyme, how I am going to save my home I have lived in since I were 6 yrs old...now due to funding ALL my own and their treatment I can no longer afford..their repossessing my home.....given hours to live on many occasions but God must of known my kids would need me...but do you feel any guilt, at all? no I didn't think so...I was bitten on top of already having it..sort of thankful or my family would never of known why their lives were falling apart..ages from not 2 yrs old yet to my 30 yr old son... traveled thousands of miles over the years looking for help...to no avail as fund wouldn't allow me to carry on treating...do i feel sorry for myself..NO..I feel sorry for you because God see's all and if you dont answer for it now, mark my words you will...Am I angry..not because anger only hurts us and not you...but thank you for giving me the opportunity to rant at now am, while laying here suffering physically and mentally..if Lyme doesn't kill me/us..worry will..IN THE NAME OF GOD WAKE UP! Hitler had nothing on the ignorance of you guys..money, arrogance , ego...to all those we have lost due to your ignorance..may they RIP

Marilynn Woodcock *A photograph was taken of Lyme bacteria in my blood after I had been on antibiotics for 3 years, yet you claim that's not possible. Not only should the IDSA update its guidelines to reflect the TRUTH about the existence of chronic Lyme, the CDC should also update its diagnostic criteria. Shame on all of you. I feel sorry for your patients.*

Donna Baez Brunner To see all members of any Committee, especially Lyme Disease and it's too many to name co-infections, removed, who has any financial interests in patents, sits on an Insurance Board, or has ANY conflict of interest whatsoever, and replaced with physicians who will listen and work with the physicians who are on the front line of treating this hideous disease to establish a HUMANE standard of care. However, I live in the real world, so at the very least, to allow physicians some leniency in treating as they see fit without fear of a witch hunt resulting in license suspensions and removal. People are dying, losing their homes and families, their hope to live a normal life due to the ravages of these diseases to their bodies and soul because the guidelines and testing are insufficient.

Terri Schliesser What would I " to see from MY society??? MY society? How audacious can you people be? Get a real job. Something you know SOMETHING about!

Hallie Richwine Screenshots until here. (Sorry, thread is moving quickly and I need a good way to see the break...and I need to get some sleep!)

Corinna Lyme Lehman i would like for the IDSA nazi's to stop laughing at me during every ER visit. i'll tell you again... its not HIV, its not lupus, its not crohns or hepatitis, it IS late stage Lyme. yes i AM "one of those" as i have been told. this isn't a cry for attention, its a cry to get my life back, my son's life back, my mom's life back, my cousin's life back, my aunt's life back and the lives back for all my Lyme friends. we deserve to live and get fair treatment... don't we? love and blessings to all.

Corinna Lyme Lehman by the way, my son has a congenital case of Lyme disease and bartonella... it is VERY real everyday for the past several years for him. people need to be educated about the truth.

Crystal Desert-Diamond Carter The guidelines have ruined my life. I am 23 years old and I have been sick for years and I could not find 1 doctor in Arizona to treat me so I had to move back across the country to live with family because I am too sick to maintain a fulltime job. I am losing my state healthcare because I am working part time to pay for my bills. Now, I will be without healthcare and I continue to get sick by the

DAY. It NEVER had to come to this - never! I should of been treated appropriately more than a year and a half ago - I wouldn't be so sick, I wouldn't of had to quit the job I loved so much, I wouldn't have lost my independence. The Lord will not allow these guidelines to stay in place much longer, He will deliver us from this evil Amen!

Jot Nirinjan Kaur I would like to see the Lyme epidemic recognized for what it is. I would like to see PROPER, EFFECTIVE treatment in alignment with ILADS. I would like to see Chronic Lyme officially recognized. I would like to see the countless numbers of individuals suffering from undiagnosed Lyme disease as a DIRECT RESULT of misinformation from IDSA to stop.

At age 13, after 9 weeks of illness and one week in the hospital with 9 different specialists tending to me, thank God the infectious diseases specialist ordered a Lyme test, though I had none of the "typical" symptoms. After the two week round of doxycycline I was deemed cured, though for the nine years since I've had severe digestive problems that completely rule my life and have caused me untold amounts of pain and suffering.
It's only from talking to another Lyme sufferer who introduced me to Under Our Skin that I had the confirmation I had suspected that it is NOT a coincidence that my digestion has never been the same since I got Lymes. Only NOW am I finally starting to get some relief from the damaged wrecked by insufficiently treated Lyme. If my first doctor had known more about ALL the symptoms of Lyme, it never would have gotten to this. If all the doctors that I have seen since I was diagnosed had been properly informed about the TRUTH about Lyme, I might've gotten the help I needed when I connected the dots for them by saying "I've had these problems ever since I had Lyme disease". Instead I got a blank stare, because for them, Lyme does not exist in Texas, it is not chronic, it does not have that wide a range of symptoms. Because YOU told them so. Please, this year, tell them the truth.

Marilynn Woodcock A photograph was taken of Lyme bacteria in my blood after I had been on antibiotics for 3 years, yet you claim that's not possible. Not only should the IDSA update its guidelines to reflect the TRUTH about the existence of chronic Lyme, the CDC should also update its diagnostic criteria. Shame on all of you. I feel sorry for your patients.

Kim DeSantis Goodwin This has been found in sperm many husbands and wives both have it such my case which i believe is how i got it, transmitted through pregnancy as i gave my precious daughter, breastmilk, blood transfusion, raw meat, raw milk, other insects and im sure many more ways. If the elisa test worked than my husband would have been treated and i nor my daughter would have been sick.

We all know Lyme was changed from a scientist from world war 2 into this complex illness that tricks the immune system, blood tests and not killed by antibiotics easily at all. In a test tube it is not being killed in 30 days -- how would it die when it changes into 3 forms plus biofilm. All the co infections are worse then Lyme itself and that doesn't get mentioned. You guys are no better than someone who has murdered and tortured people. It took me a year of research and talking to people with Lyme to learn so much. What do you do talk to the fda and cdc about bonus for keeping the secret to keep us sick so everyone makes more money. Let people think they have ms so they can be on these expensive meds forever same goes with the dozens of other false diagnosis. Sad all the people that are involved with murder. Two people on the Lyme support sites died this week from Lyme disease. One of which only had 4 months of doxy. Watching the kids suffer their parents sick and nobody able to properly help anyone.

Lisa Hilton
http://www.samento.com.ec/sciencelib/Lyme/recoveryofLyme.html
Recovery of Lyme Spirochetes by PCR in semen samples of previously diagnosed Lyme disease patients
www.samento.com.ec
Presented by Dr. Gregory Bach, at the International Scientific Conference on...See More

Teri Saah Ayoub Lab Corp positive in 2002 - it still took my husband and I one year of going from doc to doc until we found a LLMD who saved my life. During that year the co-infections complicated things, along with the disease crossing the brain barrier, resulting in 4 years of picc lines.

Lisa Hilton Why are all these studies being ignored?

The Case For Chronic Infection:
Evidential persistence of Borrelia species post antibiotic exposure in vivo and in vitro-
http://www.Lymekick.com/chronicLyme.pdf

New class of Toll-Like receptor ligands capable of enhancing autoimmunity-

http://www.ncbi.nlm.nih.gov/pubmed/
Long-Term Antibiotic Therapy Improves Persistent Symptom
http://www.ilads.org/files/publications_stricker__.pdf

Research Showing Transmission of Other Than Ticks- Detection the infection with Babesia spp. Cytauxzoon felis and Haemobaronella felis in stray cats in Mosul
http://www.vetmedmosul.org/ijvs/media/conf--e.pdf

Ticks and mosquitoes as vectors of Borrelia burgdorferi- http://www.ncbi.nlm.nih.gov/pubmed/ordinalpos=&itool=EntrezSystem.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

Recovery Of Lyme Spirochetes By PCR In Semen Samples Of Previously Diagnosed Lyme DiseasePatients- http://www.samento.com.ec/sciencelib/Lyme/recoveryofLyme.html

Adherence of Borrelia burgdorferi to the proteoglycan decorin
http://iai.asm.org/cgi/content/abstract///?ijkey=dbbbadebeccbcefdc&keytype=tf_ipsecsha

Rickettsial Research – Fighting the Bites of Fleas, Lice, Mites and Ticks
http://science.dodlive.mil////rickettsial-research-%E%%-fighting-the-bites-of-fleas-lice-mites-and-ticks/

Lyme and Psychiatric Issues:
Distinct Pattern of cognitive Impairment noted in Lyme Patients
http://www.angelfire.com/biz/romarkaraoke/Lymetim.html

Ilads Psychiatric Brochure:
http://www.ilads.org/Lyme_disease/Psychiatric_Brochure__.pdf

The Role of Neuropsychology Testing Lyme In Children
http://www.Lymeinfo.net/Shea-Leventhal.pdf

The Neuropsychiatric Assessment of Lyme Disease
http://www.mentalhealthandillness.com/tnaold.html

References for Psychiatry and Lyme/Tick-Borne Diseases
http://www.Lymeinfo.net/psychbiblio.html

The Human Side Of Lyme
http://www.thehumansideofLyme.net/

Lyme Disease, Comorbid Tick-Borne Diseases, and Neuropsychiatric Disorders:
http://www.psychiatrictimes.com/display/article//

Understanding The Puzzle Of Chronic Lyme
http://www.cumc.columbia.edu/publications/in-vivo/Vol_Iss_aug_/index.html

Can Lyme Cause Psychiatric Disorders?
http://pn.psychiatryonline.org/content///.full

Diseases Of The Mind
http://www.thedailybeast.com/newsweek////diseases-of-the-mind.html

Spinal Fluid and Brain Tests
http://www.columbia-Lyme.org/patients/ld_spinal_fluid.html

Lyme As Related To Other Diseases
Lyme and Autism-
http://www.ilads.org/Lyme_research/Lyme_articles.html

Multiple Sclerosis and Lyme Disease-
http://www.direct-ms.org/pdf/CausalSpecific/MS_LymeDisease.pdf
Distinct Cerebrospinal Fluid Proteomes Differentiate Post-Treatment Lyme Disease from Chronic Fatigue Syndrome
http://www.columbia-Lyme.org/research/featured_research.html

http://www.aldf.com/Best_advice_about_Lyme_disease.shtml

A Critical Appraisal of “Chronic Lyme Disease:
http://www.nejm.org/doi/full/./NEJMra

Lymerix
Did Lymerix Cause Neurological Impairment in Recipients?
http://pn.psychiatryonline.org/content///.full

General Lyme Articles
Amy Tan- Lyme Disease
http://www.igenex.com/tickedoff.htm

A Disease In Disguise
http://www.thedailybeast.com/newsweek////a-disease-in-disguise.html

Treatment Of Lyme Disease
http://www.columbia-Lyme.org/patients/ld_treatment.html

Lyme Disease and Psychiatric Disorder
http://juno.cumc.columbia.edu/psjournal/archive/archives/jour_vn_.html

Spirochete Adhesin DbpA Influences Spirochetal Binding to Decorin
http://iai.asm.org/cgi/content/abstract///

Analysis of the dbpBA Upstream Regulatory Region Controlled by RpoS in Borrelia burgdorferi
http://jb.asm.org/cgi/content/abstract///

General Lyme Research:
Rickettsial Research – Fighting the Bites of Fleas, Lice, Mites and Ticks
http://science.dodlive.mil////rickettsial-research-%E%%-fighting-the-bites-of-fleas-lice-mites-and-ticks/

Spirochete Adhesin DbpA Influences Spirochetal Binding to Decorin
http://iai.asm.org/cgi/content/abstract///
Clinical effects of fluconazole in patients with neuroborreliosis
http://www.ncbi.nlm.nih.gov/pubmed?term=Eur+J+Med+Res.++Jul+%B%%%A-

Compounding for Lyme disease
http://www.modernmedicine.com/modernmedicine/Community+Practice/Compounding-for-Lyme-disease/ArticleStandard/Article/detail/?contextCategoryId=

Peer Reviewed Articles:
Carbamazepine in the Treatment of Lyme Disease–Induced Hyperacusis
http://neuro.psychiatryonline.org/cgi/content/full///

Functional Brain Imaging and Neuropsychological Testing in Lyme Disease
http://home.pon.net/caat/Lyme/brainimaging.pdf

Higher Prevalence of Antibodies to Borrelia Burgdorferi in Psychiatric Patients Than in Healthy Subjects
http://ajp.psychiatryonline.org/cgi/content/abstract///?ijkey=cfbcedfbbaeff&keytype=tf_ipsecsha
Late Stage Neuropychiatric Lyme Borreliosis Differential Diagnosis and Treatment
http://www.wadhurst.demon.co.uk/Lyme/Lyme.htm

Lyme Disease- A Neuropsychiatric Illness
http://www.angelfire.com/biz/romarkaraoke/Lymeart.html

Musical Hallucinations In Patients With Lyme Disease
http://www.highbeam.com/doc/G-.html
Regional Cerebral Blood Flow and Cognitive Deficits in Chronic Lyme Disease
http://neuro.psychiatryonline.org/cgi/content/full///

Seasonal correlation of sporadic schizophrenia to Ixodesticks and Lyme borreliosis
http://www.ij-healthgeographics.com/content///

The Underdiagnosis of Lyme in Adults and Children
http://flash.Lymenet.org/ubb/Forum/HTML/.html

More IDSA and other Lyme Related Info
http://www.actionLyme.org/index.htm

Teri Saah Ayoub I won't bore you with the details of what some of the docs put my husband and me through as some of them are just too humiliating to post! We thank God everyday that we found the most incredible LLMD who has helped me put my life back together pieces at a time. I wish is to see more LLMD docs teach protocol to IM's andID's - maybe just maybe they will see the positive results themselves and start to be unable to turn the other way.

Sheri Souch I want the TRUTH. Scrap your Lyme guidelines and start over. There are too many Chronic Lyme sufferers (many of whom have been cured with long-term antibiotic treatment - myself, for example) for you to ignore. You are not only causing suffering in your own country, your faulty guidelines are causing pain and suffering here, in Canada too. Enough is enough.

Matt Halter IDSA guidelines are an impediment to treatment. Eight years of IDSA docs, thousands of dollars wasted on useless tests and specialists, leaving me with a wife who became sicker and sicker. Their best diagnosis "depression". The only thing to reverse the suffering long term IV antibiotic treatment for Neurocognitive Lyme. 18 months and counting. But we had to search long and hard to find a doc willing to manage the IV treatment. Too much persecution from Insurance companies using IDSA guidelines as a weapon to shut them down. OPEN YOUR EYES TO THE TRUTH. Come and visit the Lyme support groups in the south central and southeastern parts of Pa. We can introduce you to many real life examples of what you claim doesn't exist.

Lynn Olson-Tuma I want the IDSA to stop the senseless and completely unnecessary suffering that their awful & not-based-on-reality guidelines have caused to so many Lyme sufferers, their families & their Lyme-literate doctors. I also want all members of the IDSA that have perpetrated this suffering to be relieved of the duties as a physician for they have not upheld the Hippocratic Oath.

Stephanie Pate I want my life back. Your incorrect guidelines on Lyme treatment has misguided doctors across the US and has thus stolen 7+ years of my life. Now I am having to watch my small children suffer with Lyme that they contracted in utero. Your guidelines are making it hard for my babies to get proper treatment. I want Lyme disease to be seen for the life altering/damaging disease that it is.

Michelle Perry Not much more I can say to add to what everyone else has. I just want my life back and its unfortunate our future lies in your ignorance. Please change these guidelines for CHRONIC Lyme Disease. I have missed so much of my daughters first 8 years because of being disabled...misdiagnosed for so many years because doctors are using your terrible guidelines to diagnose and treat patients. If you didn't say this was such an easily cured disease maybe we would have some real research done and a cure. Or maybe you have one that you are not sharing because your making so much money off of our suffering!!!!!!!!!!!!!!

Shelly Scott Don’t u know they cant change the guidelines the fall out would be much too great. What happens when someone admits they were wrong and many ppl suffered and died as a result? U guessed it! That’s why the guidelines stand as they are.

Kenneth Mercure Revise the IDSA Lyme Guidelines!! Because of these guidelines I went undiagnosed for nearly seventeen years, five of which was spent being rejected by doctors and misdiagnosed. This has caused many complications and is making the healing process more difficult. Even now it is extremely hard to find anyone in the mainstream medical community who believes in my diagnosis.

As soon as doctors see my medical record I am treated differently or even worse----humiliated. Even with so much evidence right in front of them, many of the doctors I still must see (due to location) completely ignore my Lyme diagnosis. It's like talking to a brick wall most of the time.

Financially, I have also been put into a position where it's either travel across the state to get help or don't get better.

In terms of insurance coverage I am extremely limited in my choice of doctors.

Because of the IDSA's influence over insurance companies, my antibiotics are barely covered and must be fought for tooth and nail upon each refill. I fear everyday how I am going to be able to afford my medications, as the better they get, the more expensive they get. This is a very important issue to me because my insurance will likely not cover these medications and I am not rich. I can only afford to pay for so much. This doesn't even include the multitude of vitamin supplements I am prescribed to take.

My struggle is by no means a unique one either. This experience is universal to nearly all Lyme patients. Unlike many other illnesses we must fight to prove we are sick because we suffer from an invisible disease. This leads to questions and disbelief from doctors and even loved ones.

No person deserves to be treated like this, whether they are chronically ill or not. Stop the conflicts of interest, put together an unbiased guidelines panel with no financial incentives tied to their opinions and help to get people healthy again, not to line your own pockets!!

Carolyn Fox Why not consult with the experts, Lyme Doctors from ILADS, who have been successfully treating these complicated cases that others dismiss. It took 20 yrs to finally get a proper diagnosis, despite multiple Western blots and Elisa tests. These are horribly unreliable and your guidelines make it even more difficult to get an accurate diagnosis and most dr's are unaware how bad they are. After being deemed the healthiest sick person at a peripheral neuropathy center in NYC and sent on my way, I'm so glad I didn't give up on finding a diagnosis(es) or the Lyme, and coinfections would have killed me. Now at the peak of

Pam Ritzenthaler I'd like 'my society' to READ all of the Lyme Disease studies - not just those studies written by IDSA members. I'd like IDSA to engage in SCIENCE where scientists learn from each other and use each others' studies to build on the body of scientific knowledge rather than to tear down opposing views. Science is supposed to be a conversation not combat and not protection of any one viewpoint / profit center. I'd like IDSA to turn just as critical an eye on Lyme studies conducted by IDSA members as it does on studies by ILADS members. I'd like 'my society' to understand that Lyme Disease is complex and that it manifests differently in each patient and that it, in many cases, does NOT die with 2-6 weeks of antibiotics. To say that the IDSA guidelines are sufficient is to ignore the experience of tens of thousands of patients who did not get clear of their borrelia infection after IDSA standard treatment.

Shari Blanchard I would like the guidelines for Lyme Disease revised. If 'Lyme' is not responsible for the continuing symptoms after the initial Lyme infection, then what are so many people sick with? Lyme is growing faster than AIDS and West Nile combined and for many the symptoms continue on. Those of us dealing with ongoing health problems after presenting a bulls eye rash cannot even get appropriate medical help. We will not stop applying pressure to the IDSA until we get the medical help we need.

Carolyn Fox *My career, I am unable to work and live a normal life. And what about all of the children that are not being properly diagnosed, and are doomed to suffer slow CNS damage and not have a productive life...update the guidelines now please!!*

Debbie Ray Thank you Lisa Hilton for all the great links.

Jason Catlett Wow, You would think the IDSA would do something about this. I don't have Lyme Disease, but my girlfriend has Lyme. She has had it for over many LONG years now. And everyday out (store, mall, ext...) I meet people who have LYME. All these people all over the world are complaining about the same thing but Lyme doesn't exist. Sounds like all members of the so called IDSA, should admit they have no freaking clue on what there doing or talking about, and quite. Get new people in that would have an OPEN MIND, instead of being one sided. It must be a Doctors thing. You all suck.....

Yvonne Forey A member of the IDSA himself speaks the TRUTH..yet you ignore one of your own? http://www.youtube.com/watch?v=V-lHDATM

Carolyn Fox My career, I am unable to work and live a normal life. And what about all of the children that are not being properly diagnosed, and are doomed to suffer slow CNS damage and not have a productive life...update the guidelines now please!!

Alisa Gremore Just because something can be very hard to treat and can be very confusing and expensive does not give us a license to say it does not exist. I could not be told I did not have Lyme disease because I had multiple em's. This Dr. walked or paced the floor in his office playing with his hair. WHY was this Dr. so scared and nervous??? Why the LIES?? And furthermore, to be on the safe side do not tell people any tick is harmless, the dog tick MIGHT NOT be harmless and when you have people, very sick people with IV's pumping in their veins all lined up in a row HIDE them when someone comes into a CDC looking for help. It was kinda hard for even my naive self to believe this clinician say it was not in MI yet with that little row of sickies in sight, at least draw a curtain. And if I have the name of the state place I went to wrong don't blame me sweetie blame the tick!!!!!!!!!!!!!!!!!!!!!!!!!!! Stop the lying, a president of the U.S. had some form of borrelia for God's sake and he lives in a non-endemic state.

Michele Lott The question posed here simply adds insult to injury: OUR society??? Who are you fooling??? Yourselves, of course, once again. It is utterly shameful how much ignorance and lack of compassion the IDSA has consistently shown in regards to research and the terrible misery of Lyme disease patients. I am a member of several support groups, some members of which have also had cancer. IN THEIR EXPERIENCE, LYME DISEASE HAS BEEN MUCH WORSE, BOTH TO TREAT + TO LIVE WITH, THAN CANCER. Shame on you, IDSA, for obfuscating the truth, clinging to your egos, condoning bad science, and lining your pockets with money made from keeping people severely, and sometimes fatally, ill.

Nicole Gallagher Do the right thing for Lyme patients! I am one of 6 in the same household who got Lyme, 4 from tick exposure, 2 congenitally. 11 years later, despite fighting for our lives, we are not all well yet. We need honest science and medical support to fight this multi faceted invasive disease and it's cousins. Do the right thing and educate the medical communities of this country to detect and properly treat this disease.

Lily Bayrock Hi guys,

I'm afraid we might end up going down the road we sometimes stumble down and lose our clout... Let's try to answer the IDSA's question here without going too much into our own personal stories and frustrations. I know it's hard to do, but our power here is in our numbers and our clarity of message, and we don't want anyone to be able to marginalize us anymore. Let's stay calm and rational and continue to let the IDSA know that what we would like most from them is for them to revise their diagnostic and treatment guidelines for Lyme to include chronic Lyme as a disease and long-term treatment as a viable option, and for treatment to be more readily available and more patient-friendly. This will happen with the help of recognition from the IDSA and with their support against insurance companies refusing treatment coverage and for doctors being allowed the freedom to treat as they see fit.

Did you get that, IDSA? Thanks for asking for our input. We would greatly appreciate a kind ear from you, and for you to give a new focus to Lyme and Chronic Lyme through an unbiased and open-minded interchange with chronic Lyme sufferers and Lyme-literate doctors, and we look forward to working together better in the future. We can't lose sight of the fact that we all share a common goal: to end suffering through diagnosis and treatment of infectious diseases, and we, chronic Lyme patients, would like nothing more than to extend the IDSA's knowledge and treatment base to include this disease which continues to be under-diagnosed and under-treated.

Happy New Year!
Lily Bayrock

Cindy Jeane How about changing the way Lyme disease is tested? I was told for 15 yrs that my Lyme tests were negative, that i DIDNT have Lyme disease repeatedly..it was only when i went to a LLMD that my test finally came back positive. How is one to know that a normal everyday labs testing is so very innacurate?....the medical community should be ashamed of how little they know about this disease...pathetic!

Todd M. Couture Seeing my very close dear friend of mine deal with the years of agonizing pain because of her Lyme they need to change the guidelines because more and more people are contracting it and living thru the pain and disease.

Keri Ellington Aragon add me to the list of people who want the truth, real science, help getting well, and my life back. Because of your guidelines I wasted a year of my life and tons of $$ seeing over 20 doctors from every specialty only to be yelled at, ignored, and offered some seriously scary drugs. I was a second grade teacher, but I lost my job because I could find a doctor to help me. What a sad world these guidelines have created. Please think about the people and do what you know in your heart is right. We're dying out here and you can change that.

Lori Johnston Aguilera That doctors would be committed to research and treat this disease, as they would any other, because they want to cure people, and stand against the politics that makes it difficult to do their job.

Anne Goude Mears Write guidelines based on real evidence, not expert opinion that limits choices.

Yvonne Forey I agree Lily but no insurance in the UK...no doctors, no empathy what so ever..we had 3 doctors all been squatted by the powers that be....people have been sectioned for speaking up over here too...on google for all to see, till proven the lady did have Lyme of course...its hard not to rant as I am sure you understand. But yes we should try ...to enable us to get the care we need we need to be well enough to fly to the USA or wherever the LLMD's are..impossible for myself and many others...gut wrenching to watch my not yet two yr old grandson screaming in pain, not to mention many of my family...but yes..lets hope and pray this is our year for all in this thread and beyonds sake...

Pat McDonald Just look at this!!! It's criminal!! That's what you are and will continue to be if you keep ignoring.....If it was your Child...spouse...Mother of Father you would treat them..NOT by your guidelines I am sure.!!!!!

Sue Aldous Too many suffer because of your flawed guidelines. The economy would be much better if the sick got well enough to work. Focus on the cure but untill you figure it out let us be treated with dignity and what meds we need.

Mabel Quinones I would like for the hypocratic oath to include the Lyme community. I want the lies to stop. The truth will prevail, it always does. What side will you be on IDSA? I have chronic Lyme, my daughter has it, &

now my husband. Mothers can pass it to their unborn babies, & it can be sexually transmitted. People have become ill from donated blood...how many more will you allow to suffer, & for how long?
Jacqi Euler I gave it to my son, and now my husband as well. When will this madness stop?

Melissa Muthig Hotmer Please help us fight Lyme disease. Help those get properly tested. This is so getting out of hand and needs to be stopped. My life has been turned upside down because of it. PLEASE HELP US!!!

Cindy Bennett Stoesser I would like you to STOP ignoring late stage chronic LYME disease! I had a tick bite 40 years ago - and didn't get antibiotics for it until 2 years ago! Now I will be on them for YEARS, probably off and on for the rest of my ife. My Insurance will not pay for them now because YOU don't believe I have Lyme! You should be ashamed. I hope and Pray that knowone close to you ever is stricken with this disease. No one should know this pain and suffering. My family is sick because I was not diagnoised in time. I believe I have lost family members to Lyme that were told they had other diseases because of your ignorance - This has to stop - You can make it stop. Change your ways and make things right. Stop the suffering. Save us.

Molly Perry Help those that are suffering with Lyme Disease and Other tick Borne illnesses!!! How can you ignore all of these people? Obviously this is real!!!!! You see $$$$$ I see manslaughter!

Dane Henrikson Are you joking? Your company should be burnt to the ground with misleading guidelines to save a buck. You all should be ashamed of what you represent. My wife and child almost died because of Lymes and now I have been diagnosed. Doctors can't cure what they have no training about due to your guidelines that protect a greedy group of people. Insurance will not cover this illness. After we treat the members of our family. We will be forced to live off the grid, and I have lost all faith in this corrupt system that has grown so ugly and evil that places greed before health. America was founded in a time when people feared for freedom. Now we have to worry about the chemicals being sprayed in the air to make us sicker.

Jennifer Cowfer Roe "Mission IDSA’s purpose is to improve the health of individuals, communities, and society by promoting excellence in patient care, education, research, public health, and prevention relating to infectious diseases."

I'd love to experience the patient care, but no infectious disease doctor will touch or test for Lyme in Alabama. I'm wondering about the education, because 5 of my family members in PA have been bitten by ticks this year and each were sent home with different information and prescriptions. One was told that there is no Lyme in PA. One received one day of an antibiotic, one 2 days, one 10 days and one was given thirty days but told to not even get it filled. So even your own doctors following your guidelines are confused.

I have had chronic Lyme for 31 years. I would never have taken the chance I'd pass it on to a child if I had been diagnosed. I'd like your members investigated by an independent panel and all those with conflicts of interest, (i.e., pharmaceutical ties, insurance ties, vaccine ties) to step down. There are plenty of doctors available who aren't corrupted by the politics and money. I'd like to see some research into reliable testing. I'd like to see a new board come forward and allow doctors the leeway to treat their patients as they see fit. I'd like to see integrity and compassion from a medical society.

This is epidemic and the blame is squarely placed at your current guidelines' feet.

Valerie Mains Wolfer The ignorance and arrogance surrounding Lyme Disease is appalling. Put politics aside and start educating the medical community and public about Lyme Disease using clinical-based evidence and current research; revise your guidelines which are obviously outdated and doing much more harm than good; remind doctors that Lyme tests are not accurate and insist they should not be relied upon to make a diagnosis; replace the entire committe with physicians who actually have extensive research and clinical experience treating Lyme....immediately remove those with conflicts of interest or hidden agendas. Remember and abide by the Hippocratic Oath you took and start saving lives instead of destroying them.

Dane Henrikson When you see the damage this has done and watched good people lose a battle with health, it changes a person. I used to support leadership of the free country. Now I'm shocked and scarred.
Valerie Mains Wolfer Lisa, Thank you for paying respect and reminding us of all the lives lost to this horrific disease. To those who do not understand just how

debilitating and painful Lyme can be, I hope for your sake you never need to find out.

Naomi Hart to make the guidelines on borreliosis reflect the scientific evidence, as is the case with the ILADS and German borreliosis Society guidelines. IDSA guidelines not only affect those in the United States, but also in countries whose governments follow them uncritically.

Dane Henrikson Tell your stories. Let them know what were going through, and how many have died.

David Leggett Be open, don't hang onto vested interests, look at everything objectively, listen to the stories of people who suffer intensely from Lyme and tick-borne diseases. Thank you for asking.

Valerie Mains Wolfer *The ignorance and arrogance surrounding Lyme Disease is appalling. Put politics aside and start educating the medical community and public about Lyme Disease using clinical-based evidence and current research; revise your guidelines which are obviously outdated and doing much more harm than good; remind doctors that Lyme tests are not accurate and insist they should not be relied upon to make a diagnosis; replace the entire committe with physicians who actually have extensive research and clinical experience treating Lyme....immediately remove those with conflicts of interest or hidden agendas. Remember and abide by the Hippocratic Oath you took and start saving lives instead of destroying them.*

Devi Shakti Revise the IDSA Lyme Guidelines!! Because of these guidelines I went undiagnosed for years! I lost my year career as an RN, my home, my dignity and was homeless because of the corruption of the IDSA. Stop lying, stop denying. I want my life back. I lost my childrens' childhood because of you people. EVERYONE is a risk including your families. Stand up to the corruption. Stand up for the people and what is RIGHT.

Devi Shakti And all of my children have it passed from me, and my Mother passed it to me. And my ex husband is infected because of me. See a problem here????

Matthew Tyler Wow/ just, wow.

Scott Belcher More truths about Lyme disease to come out, and for it to be tested for, and treated, much earlier and often when cases occur!!!

Cindy Cummins I want accurate diagnostic and treatment guidelines around Lyme Disease that are aligned with ILADS.

Caryn Brady Truth and compassion.

Maddie Rose Find a cure. It's amazing..If you cure Lyme disease you will most likely cure most cases of Autoimmune diseases etc. OH wait then you would have to admit you are responsible for misdiagnosing MILLIONS of people and many passing away! At this point I don't care what you have caused in the past. Lets fix this. PLEASE no more suffering. :(

Steve Zoccoli I want accurate diagnostic and treatment guidelines around Lyme Disease that are aligned with ILADS as well. Went undiagnosed for 30 years! Have spent $ 80,000 on treatments that insurance companies refuse to pay for, because of your ill advised treatment guidelines. Does EVERYTHING have to be about the money in this country? PLEASE REVISE YOUR IDSA TREATMENT GUIDELINES FOR CHRONIC LYME DISEASE!!! PLEASE!

Karen Tanana Pace reverse the ILADS guidelines to include in depth treatment....access to easy diagnosis...too many oif us are suffering!~ xo

Carmen Larson I would really like to see a statement that there are no longer guidelines on treating Lyme disease. Just leave it up to how any doctor sees fit. Just scrap the whole thing. Then patients won't complain to you about your flawed guidelines, and doctors can do whatever they want cause there is no guidelines to follow.

Michelle Perry HAHAHA @ Ruth ...if only that would happen...LOL!

Jennifer Cowfer Roe Excellent, Wendy!

Lori Sullivan-Mangrum Late Stage Lyme Disease Symptoms:
Most common symptoms reported by 1000 Patients with persistent borellia infection: (% of Patients)

Fatigue: 96%
Brain Fog: 87 %
Joint Pain: 78%
Loss of Balance: 60%
Headaches: 57%
Neck Pain: 56%
Muscle Twitching: 55 %
Insomnia: 52%
Muscle Weakness: 51%
Vision Floaters: 48%
Mood Swings: 47 %
All Over Body Pain: 43%
Noise Sensitivity: 42%
Heart Palpitations: 41%
Light sensitivity: 40%
Night Sweats: 36%
Ringing in Ears: 36%
Deep Bone Pain: 35%
Low Body Temperature: 35%
Numbness Hands and Feet: 33%
Air Hunger: 30%
Migraines: 30%
Rib Cage Pain: 30%
Sensitivity to Smell: 26%

If you have 5 or more of the listed symptoms, there is a very good chance you have Lyme Disease. Remember testing is only 40 percent accurate and you should be diagnosed clinically based upon your symptoms. You will need to see a Physician who specializes in Lyme Disease treatment.

Martha Champion I would like you to STOP ignoring late stage chronic LYME disease. I have a copy of all the comments up to now, just in case. This is a serious problem and deserves real help.

Laura Uscher i would like u to all be arrested for murder because of all of the innocent chronic Lyme patients that have been denied proper treatment due to your guidelines and have died as a result of it...

Valerie Mains Wolfer It will be interesting to see how the IDSA handles all of these comments...wonder if all our comments will be ignored or deleted? I wish there was a way to send the entire link to every news station in the country. :)

Cathy Cardwell-Woodburn Take the gag order off of all the MD's and allow them to be educated on the testing, diagnosing and treating of LYME DISEASE and Co infections!!!! Allow all the people who suffer to get treated correctly so they can live normal lives.

Thane Lyme I think it would be fantastic if in 2012 you could find a faint thread of morality in your dark corrupted souls and UNBLOCK ALL THE CHRONICALLY ILL LYME PATIENTS YOU'VE BARRED FROM COMMENTING ON THIS PAGE!!!

Puma Of-Thenorth I agree completely with Thane and want to know why I have to post using my cat's facebook account when the real criminals are the people who write purposely misleading Lyme disease & co-infection guidelines harming so many lives. I hope one day there is a class action suit and some of the people who keep writing phony guidelines go to prison.

Michelle Perry They blocked you????? UNREAL!!!! So I assume we will all be blocked after they see this???

Sara Schultz For starters, you could help put an end to the pharmaceutical industry's funding of medical schools.... personally I've always thought that there might be a SLIGHT conflict of interest in that area, don't you?? Also -- please quit bringing your IDSA conferences to Canada. THANK YOU !!

Jeff Christnagel
Http://www.facebook.com/nondeployedgwi more gulf war illness; coinfections in the population. Lyme relation

Denise Weaver I would suggest you help me and all of the aforementioned as we will soon die without your help....Chronic Lyme Disease and Its Co-infections

Nani Lauriano Luculescu honest guidelines for Lyme disease...the status quo is shameful and misleading at best.

Kathy Obal Carlstrom I would like to see the retraining of every infectious disease doctor in the USA, so that the broad degree of misinformation about Lyme Disease and co-infections (mycoplasmas, etc) which has been professionally disseminated to this group of MDs can be unraveled. Professional retraining coursework should be mandated for all ID doctors since the problem is now so severe and dangerous to public health both nationally and abroad. ID doctors have sadly been some of the most ill informed doctors I have come across and are unequipped to deal with the very serious diseases they should have been trained to treat.

Mel Thornburg S.O.S. we have heard for 35 yrs...I don't expect you to help the people now...What you should do is return all those funds from doctors who trusted you so they can do the research we have had to do to survive. Be Gone with you.

Marc Hope Put Lyme on the map. Give a clear and easy way for infectious disease doctors to explore testing and treatment options. Even if that means long term treatment.

Carol Connolly I would like to see my society speak out and have the members of the IDSA with conflicts of interest LEAVE, and have their replacements make policy based on scientific studies.

Marissa Bella Cassella IDSA- I and thousands of other Lyme patients would love for you to change your perspective on CHRONIC Lyme disease. By changing your perspective, I mean to admit Lyme is chronic, that ticks are found basically everywhere due to travel, that thousands are being misdiagnosed with other autoimmune diseases (i.e. Lupus, MS, ALS, Chronic Fatigue, etc), and takes longterm antibiotic therapy in order to go in remission from Lyme and co-infections. Lyme disease is a serious disease and has even killed some patients. If you are as reputable as you claim you are with infectious disease, why won't you give proper information on Lyme disease? 2012 is a new year, a fresh start. Please start saving lives.

Marissa Bella Cassella Oh, also please admit that Lyme disease diagnostic equipment is very outdated due to it's sensitivity level, which is why many Lyme patients come back with a false negative. Please stop misleading us all!

Monday Mercer My mother died from undiagnosed Lyme disease. She passed it to all her children. I have now passed it to my daughter. I am now 61 and basically bedridden since I have had this my entire life and only discovered I was positive 3 years ago! As soon as I was diagnosed, I immediately knew what my mother died from and what was wrong with my daughter. Haven't enough lives been ruined by your faulty guidelines? Doctors need to study chronic Lyme disease in school--learn how to diagnose it and how to treat it. Insurance companies need to cover to expenses for treatment until a person is well! Our medical system has become that of a third-world country! Change the guidelines NOW and start educating the medical profession today. How many more people have to die?

Debra Rice I would like the IDSA to act like a society with morals. I would like you to actually READ the 357 (and counting) comments on here, rather than reacting with anger and defensiveness as usual. I would like you to truly think about every person, and every story on here, instead of deleting the post, ignoring us, blocking us, calling us all crazy or hypochondriacs.

I would like you to answer for your actions (and lack thereof). To hold yourselves accountable for the countless wrongs done to the growing number of Lyme patients (people who fight EVERY DAY to pull themselves out of the devastating quicksand of Chronic Lyme and Co-infections).

I would like you to think of us as individuals, rather than a faceless group. Then look at yourselves in the mirror, ask yourselves if you would treat your friends, your significant others, your children, and yourselves the way you've treated all of us. I would like you to advocate for US, rather than for yourselves, your wallets, and your professional accolades.

Every one of us has been through hell. Many of us are still there, and may never leave, because of YEARS of being misdiagnosed and mistreated. I'd like you to acknowledge this, and admit the part you played in sending us there. You can't ignore and discount every single one of us (and all those who have tragically died from Lyme) anymore.

You're going to have to answer for yourselves eventually. You may as well do it now, before even more lives are destroyed.

Donna Zukaitis Falcone I want you to swallow your pride, admit that Chronic Lyme DOES exist, and change your recommendations by removing the time constraints on the course of treatment so that insurance companies can stop denying treatment on YOUR say so.

Amy Holbrook Carr I would like the ISDA treat Lyme like an infectious disease - with long term treatment, like AIDS or Tuberculosis for example receives. You have such a major epidemic with Lyme disease and it is spreading so fast we will soon be not only literally paralyzed but figuratively paralyzed. I am aware of four people in my area on disability due to Lyme Disease. BTW, I am typing this with two fingers because they are my only two that can move correctly. Help some people man, and soon!

Debbie Magnus I would like to see up to date and accurate guidelines for the diagnosis and treatment of both acute and chronic Lyme Disease. It is hard to understand how in our modern society and in this country, that there would be so much ignorance and misinformation about this illness - especially in the medical community. If the CDC guidelines were updated to reflect the scientific evidence, as in ILADS, patients would be diagnosed sooner, suffer less, and medical expenses would be reduced dramatically. This disease is an absolute nightmare for patients and their families when diagnosis and treatment are delayed.

Chuck Balzer Wake up and admit that the Lyme Disease epidemic is real and you have been wrong about Chronic Lyme. It is the highest level of cruelty to label sick individuals with Lyme as having symptoms that are psychiatric in origin. Dr Jemsek (sp?) said it best; (paraphrasing)"When my critics, or someone close to them get Lyme, they will change their opinion / open their mind, and seek treatment such as I am providing"

Silvia Scherer England I wish on them nothing but Lyme disease,undiagnosed and untreated for 10 years then they would know what are we really go thru.nothing having Lyme, live with it to believe it!

Cynthia Leonard I have so much to say to the IDSA about Lyme disease and their lack of transparency in trying to understand, diagnose and treat Lyme. I wish they would stop their war with ILADS and doctors who disagree with the IDSA guidelines. Mostly I wish IDSA would stop falsely influencing doctors and permit primary care doctors to treat Lyme with their best medical judgment without prosecution.

Mary Harrison Change the Lyme disease guidelines so they are based on more current scientific findings and less on opinion.

Brian Burkett I would like you to find out WHY every woman and man with Lymes/coinfections of Bartonella, Babesia and Mycoplasmas , Soldiers and spouses with Mycoplasma Fermentans are INFERTILE or have children w/ serious birth defects. You KNOW what is going on....it's time to tell the world what you did and why it's being covered up.....

Bettyann Senf As previously stated, Change guidelines for diagnosis and treatment, stop the persecution of LLMD's, educate primary care drs as that is where the misdiagnosis starts, and admit there is chronic Lyme and co infections. All these people posting have real issues/ symptoms and need treatment. Insurance and SSD need to recognize chronic Lyme and support patients not deny them coverage so they can save $$$$. It is just wrong!!!

Marcie Stefaniak Donovan The testing for Lyme disease has to be more accurate. Many people are suffering with this horrible disease and it is not even being acknowledged as a real disease. Also, two weeks of abx is not cutting it. Long term abx treatment is sometime needed for a cure and IDSA guidelines doctors are not treating right. Please take these comments seriously.

Tara K Watson I will re-iterate what everyone above me has said...recognize chronic/neurologic Lyme exists! I went 20+ years without diagnosis! I was 10 years old when I started getting crazy unexplained symptoms - I've been diagnosed with everything with my (now former) PCP diagnosing me.

Susie Rosenberg I'm a physician, and I'd like IDSA physicians to behave in a physicianly manner: know what you don't know. Be curious. Be compassionate. Listen to a patient's history as if you don't already know the answer. Sponsor REAL research: the kind that isn't set up from the beginning to give you the answers you seek. (Such as requiring the documented presence of a rash for study admission, then concluding rash is an essential component of the presentation.

Dave Marsh After a tick bite almost 10 years ago, with a full erythema migrans rash. I was misdiagnosed for 7 years by about 30 Drs., including multiple specialists at Mayo Clinic. I've had nerve and tendons damaged, constant tinitus, neurological problems. I also developed diabetes, high blood pressure and unexplained high cholesterol. These are just a portion of the problems caused by my Chronic Lyme Disease and multiple co-infections. I've seen my LLMD lose his license for unknown reasons, I believe he saved my life! We who suffer with this horrible disease are constantly offended by the CDC's stance that Lyme is hard to catch and easy to treat. My wife was successfully treated for early Lyme, because of our awareness. My daughter is being tested properly now for Chronic Lyme, and a close friend of mine recently had a positive Igenix test, and is now being treated for late stage Lyme and co-infections. We all live on the Illinois / Wisconsin border. Chronic Lyme is an epidemic! Please address this disease properly to keep thousands of other people from having to go through what so many of us have had to endure.

Tara K Watson I've been diagnosed with everything, with my (now former) PCP diagnosing me as being a hypochondriac. I have suffered and lost out on most of my life because of this disease! The last few years have been an absolute nightmare...I don't test positive for Lyme, but I have brain scans to show the damage. Look at the evidence...look at the stories...realize more money needs to be provided for research and the guidelines need to be completely overhauled. If 3 years ago I was only given the standard course of doxy, I can guarantee I would either be dead or would be in a nursing home today.

Alan Burdge WOW!!!!!!!!!!!!!!!!!!!!
IDSA CAN RUN BUT THEY CAN"T HIDE FOREVER!
HOW MUCH LONGER CAN YOU KEEP A LID ON THIS DISEASE?????
I SAW THE AD ON THE JUMBOTRON IN TIMES SQUARE!
LYME DISEASE GROWING FASTER THEN AIDS!!!!

Alan Burdge I HAVE SEEN TURTLES THAT MOVE FASTER THAN THE IDSA.
WE WILL ALL BE DEAD BEFORE THE IDSA CATCHES UP WITH THIS DISEASE!!!

Brian Burkett At this point, I have interviewed + soldiers, spouses, Lyme patients/spouses and many of them are infertile if not on ABX . Most women suffer from Endometriosis and progress to Polycystic Ovarian Disorder. This illness, Lymes and Infectious Mycoplasmas cause INFERTILITY!!!

Kim Tarbox I would like to sincerely thank you for asking and am praying that these answers while emotional, are taken to heart by your organization and we can all fight this together. There is so much power in forgiveness and this is the time to move forward ....together. I pray that someone responds and does not allow all of these pleas to remain unvalidated. Respectfully ...

Brian Burkett My information is not from some website, my information is from talking to REAL people. Every day I meet someone new who is ill with this but has no diagnosis, or has been diagnosed with one illness, but having several other undiagnosed symptoms.

Sherryn Jackson I live in Australia and you ppl hold the key for us to be treated properly as government here go by your rules. My 4 yr old and I both have it and maybe my other two as well my husband is watching us die before his eyes knowing nothing can be done. What happens when it is one of your family? Will you Change the rules? Allow the info to get out and allow Drs to treat patients properly

Jenny Guzdek I believe once Lyme is recognized, our nation's health insurance and economic issues will take a turn for the better.

Brian Burkett One girl i interviewed has classis Lyme symptoms and was given a short course of ABX, told she was fine, now she has IBS, CFS, Neuro issues, migrating joint and mussle pain AND A HYSTERECTOMY AT 25 YRS OLD.

Jenny Swart Rush Step forward freshly...look at the evidence (sick people), talk to the doctors treating them, be honest...working together a difference can be made for tens of thousands of people who want to be healthy and work and enjoy their family responsibilities.

Jane Webb I would like for IDSA to re-evaluate their guidelines in regards to the treatment of Lyme disease. Long term antibiotics is the only treatment to offer hope to those patients. I think that physicians should be able to treat based on their best judgment and the informed consent of the patient. Thank you for for this opportunity to voice my opinion.

Kelly Demers It is so disgraceful.. Do you see all these comments IDSA?? We are sick.. Not being treated as human beings. We want what is fair.. To be healthy again... Wouldn't you? We are angry, because you do not listen. What happened to our human rights? Its disgusting that after how long of us yelling for help, you now you ask such a question?? You are playing God with human lives.. Get off your high horse, recognize the issues.. They are right in your face.. We need help, better treatment, better knowledgeable physicians, and the most important thing... ALLOW the physicians to treat us according to our bodies. No by what you think is the treatment plan..

Since being sick, with chronic Lyme, my eyes have been open.. I am saddened by my own government, By you, by Pharmaceutical companies. By physicians that follow your ignorant guidelines. By how you black ball Physicians that truly care and are trying to treat us. I have never disliked an organization as much as I do yours. You cannot use one guideline for hundreds of thousand individuals, IF NOT more of us out there! Its right in your face, yet you choose to ignore it.. I leave you with this, We will continue to fight for our rights, we are not going away, there is so many new people getting sick, until one day the world is chronic.. I promise you, You cant keep us all quiet..

Katherine A Morrison Better educate your doctor's re: Lyme disease. Change the guidelines. I had the bull's-eye rash and the bartonella rash. Testing is inadequate. Most infectious disease docs just said there is no Lyme here. I am not longer able to work or do household chores. Health flew the coop in 2001 .

Katherine A Morrison All other conditions were ruled out. Attend ILADS conferences and learn.

Katherine A Morrison Insurance will not provide meds due to IDSA guidelines. Doc's are afraid to treat due to IDSA guidelines.

Leslie Farhangi There is too much hysteria in the Lyme area. But just because there is, doesn't mean the IDSA has to push against it. I would like the IDSA to open its mind and admit the medical community knows very little about Lyme. And that the field is full of holes -- no adequate test, no preventative treatment, and inadequate research. As a result you cannot definitively say how every single case should be treated -- you do not know enough yet. I would also like to see Lyme thought of like syphilis in that they are both spirochetal diseases, both are cured if treated early and both cause lasting and systemic damage if they disseminate.

Katherine A Morrison *Better educate your doctor's re: Lyme disease. Change the guidelines. I had the bull's-eye rash and the bartonella rash. Testing is inadequate. Most infectious disease docs just said there is no Lyme here. I am not longer able to work or do household chores. Health flew the coop in 2001 . . .*

All other conditions were ruled out. Attend ILADS conferences and learn.

. . . Insurance will not provide meds due to IDSA guidelines. Doc's are afraid to treat due to IDSA guidelines.

Dennis Damian Creative All I can say is thank God for ILADS, as three of us, (myself, my wife and daughter) all were diagnosed this year. All of us are receiving long term treatment by a caring professional. Sadly, this was after my wife saw one of you - was hospitalized because of Dr. IDSA failed to take action that could have prevented the worsening of her case. I would urge you to reconsider the guidelines regarding Lyme diagnosis and treatment methodologies before one more human being is cast aside by outdated processes.

Denise StGermain I would love for "you" the ISDA to "see" each and every one of "us" suffering from chronic tick/vector borne illnesses...I mean REALLY "see" us, Count our heads, you already know how dangerous and widespread (every state in the USA) Lyme is. Now is the time for you to step up and redeem yourselves by validating the world's people with TRUTH !!! Arm the people with facts and guidelines that reflect exactly how serious tick/vector parasites and infections are. No further research is necessary to evaluate just how devastating the effects of not getting prompt and proper medical treatment once infected. Just count the heads of those of us who know we have been inflicted. It's not that hard. In spite of the ISDA guidelines for minimal attention/treatment for Lyme spirochetes, parasites, co-infections, borrelia burgdorferi, bartronella, babesia name a few, continue to thrive in their hosts.

I am host and have been since 1998, with the medical test results (and bills) to prove it. Having been denied prompt and proper treatment (no treatment at all in my case) for the initial tick bite, by Dr Pamela Ross; who claimed Lyme was not my problem. She suggested counseling to better manage my emotions. I was discharged from her practice and affiliates by way of a letter stating my behavior as difficult and non-compliant (I wouldn't take the Prozac!). This letter preceded me EVERYWHERE in the medical community. Unfortunately for me, the ISDA guidelines confirmed Dr. Ross's ignorance and I remain infected.

Yet, I go on, I live. Forced to be my own healthcare provider while being denied by the ISDA. Who needs the ISDA's lack of responsibility any way?? There are many "other sciences" to choose from when encountering infectious diseases. Following ISDA guidelines will surely be the death of me. When the

ISDA is in agreement with the truth about Chronic Lyme and the "other sciences" proof and truth, I will be seen !!!!

I am only one. There are thousands with similar life altering stories of Lyme, Count our heads and tell the truth !!!!

We will NOT go away !!!!

Heidi Buono I would like the IDSA to focus on the true picture of Lyme Disease and associated coinfections. There are many people like myself and my three children who have been debilitated by this disease. I had nothing but grief from a IDSA member while my children stayed suffering. This is criminal and evil in origin on so many levels. We will not go away.

Sylviane Schwarz With all due respect your Lyme disease medical guideline has miserably failed me my health was deteriorating at an alarming speed after a tick bite in 2005 and I had to do something. Glad I did not wait around very ill in bed as waited for you in order to correct the wrong doing you have to humanity. Luckily I found out about ILADS and I am much, much better now. As a result The International Lyme And Associated Diseases Society (ILADS) is "my Society" not yours. Here is the link should you want to broaden your narrow minded vision.
http://www.ilads.org/
https://www.facebook.com/pages/ILADS-Lyme-Society/
Have a good day!

Ricken Patel Hi IDSA - as someone who does not have Lyme or chronic Lyme, I was struck when I looked into this issue by the gap between the strength of the IDSA's conclusion and the weight of the evidence. The history of medical science is littered with examples of mistaken orthodoxy sustained for too long by inertia. I'm sure we all share the same goal of promoting health - is there not sufficient doubt at least to make a scientific case to keep investigating this? Perhaps in research studies designed with the participation of Lyme-literate doctors?

Bryan Curtis Acknowledge the "elephant in the room," get back to the mission of saving and improving lives rather than lining the pockets of insurance and pharmaceutical companies, and perhaps even your own. Greed and pride are killers of true advancement.

Karen Durm Please direct funding to Lyme and other tick borne illnesses. We desperately need testing and treatment.

Andrea McLain Fennell All my military doctors diagnosed me with Chronic Lyme disease and prescribled me long term IV antibiotics. My blood work was positive by anyones standards. It took 3 years for them to come to their diagnosis. Believe me everything was ruled out. Even with all the tests and doctors agreement, when it came time for the infectious disease doctor to write for my medical board, he simply stated that he follows the IDSA guidelines and I could not have Lyme. What then do I have then in his opinion?? Simply something bad that has destroyed my life and career, it is very unfortunate and the IDSA sees this alot but unfortunately there is nothing he can do until the blood work is more clear or something goes terribly wrong that would suggest something else. Your doctors rely on YOUR bogus guidelines and have stopped practicing medicine! First lesson you should learn this year is "there are NO absolutes in medicine nor science". There is always more to learn and bacteria is always changing. Lyme patients only ask that you invest the time and effort into researching Lyme disease and listen to the research that has already been done!!

Wishya Knew *Proper long term treatment options for late stage Lyme Disease patients. For patients to be treated fairly. For our LLMDs to not have to fear for their jobs for seeing and treating us. For the countless doctors who have thrown their hands up in the air when I mention "the L word" and told me they were not going to discuss that disease to be free from fear and not be told outrageous LIES anymore about this disease!*

Janet DeCesare Here we go people: IDSA is not relying on science of the disease, they are more interested in relying on their opinions than fixing the problem. The guidelines for Lyme disease are so strict and controversial, it seems as though the IDSA limit certain types of diagnoses and if the Lyme patient doesn't show or have proof of having the disease, they won't get any treatment or the treatments they have been receiving are dismissed! The sad part of all of this is the prestige that IDSA carries, the insurance companies, the pharmaceuticals are making a huge amount of money off of us who have Lyme disease, and our health hasn't improved! Lyme disease is very debilitating, many of us including myself have had to resort to take a stand for our own healthcare. Because we have come to the realization that this horrible, deplorable, heartwrenching disease changes lives and can change your family's stability beyond belief!

We are being pushed around, ignored and we are sick and need help, but is anyone listening? It's like playing a game of chess, good doctors vs bad doctors, good medicine vs no medicine. Lyme disease is a nightmare that never goes away, not just for the patient but for the families. Then when we have knowledgeable LLMD's who understand the treatment protocols, how Lyme disease works in one's body, the correct medication to treat it, then you put them in harm's way, why? The mainstream medical community and IDSA are complaining about the use of antibiotics how they can induce super infections from overuse. Well, let me tell you IDSA if it wasn't for those antibiotics, I would have died back then. SO you see they do work!!!!!!

But it doesn't really come down to the costs or the money, it is all the time that has been lost, the aggravation, and the suffering that has devoured our lives and hurts our spouses and families. I was shuffled from doctor to doctor, like a deck of cards not knowing what fate was to fall on me. That's what has really hurt! I feel like you are stripping me, demoralizing me and denying my rights as a US citizen who by no fault of my own -ended up with a disease like Lyme disease. Having Lyme disease has been a difficult and bumpy road. As I have said before, if this was cancer there would not be any issues on treatment protocols or the expense, because insurance would cover it!

So whatever the outcome, I will continue to FIGHT THE GOOD FIGHT FOR LYME DISEASE and its CO-INFECTIONS, I will stand up, I won't be pushed around because I can't afford to do so. And I have also mentioned that someday, IDSA you are going to meet your maker, and when God asks you, "Why did you let so many people down, why didn't you help them, where did all the money go, how many lives have died because you didn't do the proper job of treating these victims? What's your answer going to be? Whether or not you believe in Jesus Christ, you will have to answer for this, so good luck! God Bless

Doreena Stice I would love to see your guidelines change for Lyme disease, and let people know that Chronic Lyme is real.

Kelly Smith Lyme patients need health care like everyone else. Better testing! More Lyme literate doctors! People are struggling through life, going broke paying for their healthcare, traveling many miles for help and even dying because of the IDSA guidelines.

Jennifer Ott I'd agree with everyone above me - recognize Chronic Lyme Disease. Loudoun County, VA is 35 miles from DC and the 1# region of the country for this debilitating disease. It's real and it's killing Americans, and you seem OK with that?!?

Kristie Yutzy How about you issue some guideline about Chronic Lyme Disease that are not fueled by greedy scientists/doctors who have patents on parts of the bacteria...how about you warn all the unsuspecting people in this country that Lyme is EVERYWHERE and carried by more vectors than only deer ticks....how about you WAKE UP and see just how many people are suffering with Chronic Lyme and realize that you are ruining people's lives with your treatment guidelines???

We need more doctors to treat us..the ones who are brave enough to openly practice are overwhelmed, and family doctors are so scared to mention Lyme, that they change the subject when Lyme is brought up. RIDICULOUS. Help all of us who are sick, help us regain our lives, and please, please, help us protect others and the future generations from this dreaded disease. PLEASE HELP US HELP OURSELVES AND OTHERS!

Juli Rankin Mancini IDSA=organized crime. I'd like to see the internal IDSA crooks go away in this upcoming year. I'd like to see the IDSA do what is best for those of us with Lyme and get rid of those piqued in special interests, which prevent us from getting proper testing and treatment. The IDSA makes us sicker not better...fix it!

Pam Dodd Honesty about Lyme and help for people who have it beyond two weeks of antibiotics and "you should be fine."

Wishya Knew Proper long term treatment options for late stage Lyme Disease patients. For patients to be treated fairly. For our LLMDs to not have to fear for their jobs for seeing and treating us. For the countless doctors who have thrown their hands up in the air when

I mention "the L word" and told me they were not going to discuss that disease to be free from fear and not be told outrageous LIES anymore about this disease!

Melissa Kerins Well, being disabled at the ripe old age of 27 from acute Lyme that was caught within 3 weeks from the start of symptoms and treated aggressively. Still leaves me disabled if not more and its going on 5 years.

Something doesn’t add up. its only a matter of time before the idsa members and their families get Lyme. I bet you won’t take the wait and see approach, or here is your 10 days of abx

Post from Infectious Diseases Society of America *IDSA wants to encourage open dialog, however, please note that personal attacks against the society or its doctors, foul language, and other abuse will not be tolerated on our Facebook wall. IDSA takes Lyme disease very seriously, for more information visit: http://www.idsociety.org/Lyme*

Wishya Knew AND admit that children can be born with Lyme disease and that spouses can contract it from their partner! I went undiagnosed for at least 10 years. Now all three of my children have this horrid disease (two of them CDC+ with NO history of tick bite) and my husband is now positive as well! Two of my affected children have heart problems and severe neuro problems! All in a state where "Lyme disease does not exist" according to every doctor here I've talked to about it. A friend of mine went to a doctor with a known tick bite that had a bullseye rash around it! Doctor said it's not Lyme because it doesn't exist in their state. CRIMINAL! Not to mention Lyme and it's common co-infections caused severe scarring on my larynex and vocal chords and made me have to have a complete hysterectomy at the age of 29 due to severe endometriosis. I was misdiagnosed with MS, then Lupus, then I was told I had "ALS-like symptoms" and THEN I was accused of being an alcoholic because of my hands tremoring (I don't drink!) Tame the monsters you created these doctors to be!

Lorisa Stombaugh Please revise the treatment guidelines -- stop infectious disease doctors from under treating Lyme patients and refusing treatment for people with Lyme disease. Stop the torture and tragedy of lost lives.

Kris Thecanary Sisterlyme Amen Carol Barrett!

Michele Wood Haynes Acknowledge Lyme disease and co-infections such as bartonella, babesia, ehrlichia, and other tick-borne organisms as persistent infections that require aggressive and LONG-TERM TREATMENT. The idea that Syphilis, another spirochetal infection, requires long-term treatment for Stage 2 and beyond and Bb does not is pure insanity. Bring real science back to the IDSA and medicine.

Tonya Lake Lewis Develop accurate testing for lyme and educate primary doctors. Productive members of society are stricken by this debilatating disease and the costs to personal lives and the economic status of our society are insurmountable. It is time for change!

Nancy Kelley I am BEGGING you to change your outdated guidelines and welcome some ILADS docs to be part of your board which is responsible for developing protocol for treatment of Lyme and co-infections. PLEASE, there are so many of us suffering with this disease and it is so difficult to find affordable treatment without our Doctors fearing for their medical licenses. It is totally unacceptable in the United States of America that tens of thousands of its population be treated so shabbily and with such disregard for our suffering. Please, please open your good minds and hearts to the possibility that you have been incorrect about your guidelines- I am BEGGING.

Melissa Hanks Change the guidelines for treating lyme disease please. It has taken the last four years of my life away from me, it may be too late for me now to get my life back seeing how I had been misdiagnosed for so many years. My son got infected from a tick bite and the pediatrician would only give 3 weeks antibiotics. Well guess what? As soon as the antibiotics were through he got another lyme rash and symptoms came back. Why is that? I can tell you why, because the guidelines are flawed. ONLY because I knew what to do and took him to a Doctor that knew about the devastation lyme can cause and he was treated for 5 months and the rash and symptoms went away with no other problems. There is no doubt in my mind if he had not received the extra months of antibiotics he would be a very sick little boy right now. I refuse to let the

IDSA play with my families lives because they dont want to give the public the truth.

Blessing Palyo-Herman I am trying to figure out why I've had to suffer needlessly with Lyme, fighting for treatment for myself, being belittled, trying to protect my unborn baby while pregnant--and my DOG gets a more accurate test and treatment than I did! WTH is wrong with THAT picture? Do SOMETHING to correct this situation. Why is Lyme one of the most Censored stories of 2011 from "Project Censored"?

Renee Kopek Acknowledge that Late Stage Lyme is a serious disease, difficult to treat and difficult to diagnose, that the CDC recommendations are not to be used for diagnositic purposes, that the testing for Lyme is faulty, that if not treated early Lyme is very difficult to treat. Become proactive in Physician education to make them aware Lyme is a possiblilty anywhere in the country, not just the upper East Coast. Refrain from calling those of us not diagnosed for years and years and now disabled "hypocondriacs with the aches and pains of daily living"....I only wish that was all it was.

Jan Connell *I would like to see you start meaningful work on finding a cure for Chronic Late Stage Lyme Disease and begin treating these afflicted people as human beings.*

Carrie Garman that they acknowledge how deadly this disease is and how many of us suffer greatly on a daily basis from it and struggle to make it! It’s torturous, worse than being in a cell in the war and tortured! It’s awful they act like they know nothing and its all in our heads. Look at the mice I just posted of spirochettes in the blood of a live mouse! WE the real people of the USA and all over world are suffering with these things in our bodies!!!! WILL YOU FINALLY HELP US??

Brian Burkett Lymes and Mycoplasmas cause chronic illness that causes any latent viruses to re-emerge such as HSV, HHV, Cytomegalovirus, EBV and Enteroviruses, normally these are suppressed. But by having a CHRONIC INTRACELLULAR BACTERIAL INFECTION (s) and a lowered immune system, WE CAN PASS THESE VIRUSES, BACTERIAS TO OUR CHILDREN! Listen to us, Goddamnit!

Carole Barrett I had a tick bite 9 years ago and classic BULLS EYE rash. I got sick and went to the Dr. who had NO idea what it was, neither did I... then. My health declined and I saw Dr. after Dr. BEGGING for answers! EVEN after I had a brain MRI and the DR. at the Hospital said it looked like Lyme. Finally I was in a wheelchair and was sent to an Infectious Disease Dr. who proceeded to tell me that Lyme would NOT do this to me. Maybe I had mental issues!!!!!!!!!! I have heard this story thousands of times from other Lyme Patients!

I had ALL the classic symptoms, bulls-eye rash but tested positive after years on only One band so I was refused IV drugs needed to reach the blood/brain barrier. Testing for Lyme is not accurate! We NEED better testing! Now I'm bedridden, nerve damage, severe neurological problems, damaged gut, extreme sound and light sensitivity, memory loss, etc...Lyme has taken my life and this could have been avoided! Apparently OUR lives mean VERY little. Stop denying LYME patients, we are human! We deserve compassion and treatment and pray each day this is never you or someone you love! WE need a cure for ALL of us suffering and dying!

Dagmar Weis I am suffering for 18 years !! Correct diagnosis and treatment could have prevented me from being in a wheelchair. I developed Diabetes,nerve and tendon damage, high blood pressure, untreatable high cholesterol, uncontrollable movements, went through fatique, insomnia, more then 80 symptoms.. and now it's affecting my eyesight. Shame on a system that denies proper care and treatment, shame to the country that prides itself to be a leader and super power. Heal the homefront!!!

Tricia Soderstrom My family is sinking into debt from expenses to cover medical treatment for Lyme disease and co-infections. Myself, my husband and 3 children are in treatment and have been for over 2 years. We are seeing positive improvements that only long term abx has brought about! We need better testing, we need insurance coverage for our Lyme doctors. We need our Lyme doctors to be able to treat with freedom to treat the way they see fit and support from the CDC. I agree with one of the gal's above, if insurance covered the many many many Lyme patients our economy would improve significantly because the thousands of dollars we spend every few months would go toward purchasing things that would boost our nation's economy. Someone needs to wake up to this! The proof is in the pudding! Long term abx works!

Bonnie Lieb I'd really like for you to get your heads out of the sand and see what is going on with Lyme disease. It can be devastating and it deserves the full support of the medical community.

Erin Reid Coker So many people are suffering from chronic Lyme... it's time to educate the doctors and get this under control.

Kelly Patton Nanney 388 comments! If nothing else gets your attention...... That is just a mere fraction of the suffering amount of people.

Janet Mangano I would like to have my 34 year old body and mind that I should have. I would like to be able to run with my 3 young children. I would like to be able to walk up and down the stairs without pain and cracking sounds. I would like to wake up without any pain in my head arms hands chest feet legs pelvis hips wrists elbows. I would like to walk 10 feet without getting dizzy. I would like to be able to have sex with my husband, who also has Lyme, without the pain. I would like to not have to be on a bunch of different medications from Lyme just to be able to "function". I would like to not have a "sinus infection" every month. I would like not to have ruptured ovarian cysts every month. I would like not to wake up mysteriously with pink eye. I would like not to have anxiety and panic attacks and rage. I would like to be able to go to one of my HMO doctors and not get pushed aside and tell me all of these things aren't due to Lyme.

I would've liked the ER dr who very first saw me in 2008 to had been educated enough to know that it was a tick bite and the symptoms I was suffering from we're Lyme disease and Erlichia. Not to dismiss me with "just a bug bite", and 4 years later still fighting this monster inside me. I want my life back!! There WAS NOTHING wrong with me BEFORE this horrible thing infected my every tissue and left me with just an empty shell. I would like to be able to get the proper diagnosis and treatment for Lyme disease and not just get diagnosed with fibromyalgia and a bunch of other dismissive conditions.

Why won't you help us!!???? Why are you lying and covering up such an epidemic!? Maybe if one of you or one of your truly loved ones suffers from it you would understand the torture we live with on a daily basis. Please stop the crimes!!!!!! We will not be silenced. There are too many of us dying.

Janice Baker Bittner You've got lots of catching up to do, IDSA. Your past performance re: Lyme disease and other tickborne illness has enabled these diseases to grow into complex, multi-headed monsters. You need to CATCH UP on the research, TRAIN physicians on proper, aggressive treatment, and EDUCATE the public on the dangers of misdiagnosed, under-treated tickborne diseases.

Bonnie Lieb Sorry, IDSA -- taking Lyme disease "seriously" doesn't mean 3 weeks of antibiotics, no health insurance coverage and hard-to-find doctors. It is time to seriously get serious.

James Gilbert Lyme disease has ruined my life as well. Had the guidelines on treating Lyme disease been more skewed to the disease itself and not to a foregone conclusion, my life and the lives of many people likely would have endured significantly less suffering. Shame on those who created and stand by such asinine guidelines, particularly for not giving the other side the proper time of day. Maybe it is about time to incorporate the rest of the world's opinion on Lyme into your guidelines. After all, Lyme did not originate in Lyme, Connecticut; it already existed in Europe a century earlier and has been documented.

Cindy Hall Clark I would like to see the IDSA re-evaluate its guidelines for the diagnosis of and treatment of Lyme Disease and other tick-borne illnessess in a manner that will accurately reflect the seriousness of and the proper treatment of all tick-borne diseases. Its members are not living up to the Hippocratic Oath by putting its members needs (greed) before the needs of desperately ill patients. Shame on you.

Connie Jo Havens Donahoo Put politics aside. Don't dismiss treatments that work -- especially for chronic (late stage) illness. Don't dehumanize patients as crazy, malingering, or hypochondriacs because your recommended short term antibiotic protocol isn't effective in treating their symptoms.

Eric Anderson I would like the IDSA to take their heads out of the sand regarding Lyme. "There is no Lyme in Texas", yet the Lone Star tick (found all over Texas) is a carrier of Lyme. Myself and my wife are both CDC positive. I thank God every day that we can get treatment because of this. I know there are thousands of patients out there that are positive, but show negative on the tests. IDSA, please revamp your guidelines and begin working on better testing. A few weeks of antibiotics is just not enough.

Josh Cutler I am in no way seeking pity.
But because of this disease I am 31 and on the couch as I type on my phone. I can't watch my son do the things kids do.

I can't play sports with my son or go on dates with my wife. My family sees me sick and has not a single clue what to do for me.

See before I was sick I was an upper middle class tax paying citizen with health insurance.

Due to docs ignorance and the jaded standards set by the Idsa and CDC. I went on and was passed around telling me it was in my head. Now I am too broke to pay for quality healthcare that health insurance will not pay for.

See I am bankrupt, not cause of crazy credit card balances but because of guidelines that were never reviewed by an unbiased source.

You are not only allowing people to be sick and die. But causing almost a poverty level of sick former functioning citizens.

I lay on my couch dying because you refuse to revisit guidelines and maybe then possibly my insurance will cover it so I can get the treatment I need.

Are you going to help raise my son if this disease takes my life. What about the families we leave behind or the stress this epidemic puts on the economy.

The mistakes you made have effected our country on an economical level. Open your eyes please. Have mercy on those that are suffering.

Forgive bad grammar and English. Partial eyes and neuro issues from Lyme.

Hear our plea.

Kat Holland Rinaldi some honesty about Lyme Disease, Better testing, more education to doctors about Lyme. Admit Chronic Lyme is very real and is not all in our heads , and let us decide how and what our treatment should be.Too many people are suffering we need help and proper research.

Geri Peone Tresvik Please open your minds to the devastation of chronic Lyme Disease! Honestly review ALL the available research and do additional research. Then re-write the guidelines so many of those with LD who are disabled can get treated & resume their interrupted lives.

Heather Dery Gallegos I SECOND ALL OF THE ABOVE :) :) :)

Donna Zukaitis Falcone @IDSA - thank you for that link. I viewed your video on the chroinic Lyme diagnosis/problems. Everyone knows that there are incorrect dx in every field of medicine, and I am quite sure that Chronic Lyme is no exception. BUT Dr. Paul Auwaerter's video does not address the patients who are CORRECTLY diagnosed and yet are denied effective treatment. He, in effect, is saying that because SOME are misdx and therefore treated inappropriately that ALL Chronic Lyme Patients must suffer. Where is the logic in that? He also fails to acknowledge the poor quality of the testing available and the CDCs own statements warning against using blood tests and western blots to DIANGOSE the disease... that a clinical diagnosis is necessary. Please explain and respond.

Donna Zukaitis Falcone @IDSA you cannot responsibly make the leap that because SOME patients are misdx with CLD that CLD does NOT EXIST. In fact, by saying that aren't you saying that it DOES exist... it's just not always correctly labeled? Aren't you contradicting yourself?

JoAnn O'Linger The IDSA needs to put together an entirely DIFFERENT committee to re-evaluate the guidelines for the dx and tx of Lyme... without Dr. Wormser and friends, that is. This new committee must include ILADS doctors and acknowledge the vast body of medical research that supports the existence of long-term, chronic Lyme disease, which is highly resistant to abx. It should be obvious to anyone with a brain that if a blood test shows ANY antibodies to Lyme which are highly specific to that organism, there MUST have been exposure to Lyme disease. That combined with the appropriate symptoms should be enough for a clinical dx.

Also, the fact that there are strains of Lyme disease out there which are NOT currently being tested for should be taken into account. A negative Western Blot should NEVER rule out Lyme disease!! It is utterly ludicrous to insist upon 5 antibodies out of a particular 10 for IgG and 2 out of 3 for IgM! Those criteria ensure that MOST people who actually have Lyme will NOT be properly diagnosed. Of course, the health insurance companies who fund Dr. Wormser's research are quite happy with the current status quo! The IDSA can change this horrible situation, if you only will acknowledge that bad science is at the bottom of this mess and good science can fix it. Thank you for listening!

Margaret Behrns Track the myriad of health issues that ensue after someone is exposed to TBIs. Document the different paths it takes, see the trends, and get agressive about prevention, diagnosis and treatment. There is no time to wait.

Arlice Hedge Gallagher Start acting like scientists and start seeing Lyme for what it is. I think it's responsible for the rapid increase in diabetes in this country.

Sheri Souch IDSA: It is obvious that someone is reading these comments as they are deleting the "personal attacks" and foul language. I understand why you would do this, but I hope you will also understand how desperate Chronic Lyme pts are. Many are debilitated and becoming bankrupt obtaining treatment that should be covered by insurance. Are you listening to our stories? Will you conduct an honest review of your guidelines?

Jan Connell I would like to see you start meaningful work on finding a cure for Chronic Late Stage Lyme Disease and begin treating these afflicted people as human beings.

Kaethe Mitchell Dear IDSA, thank you for reminding us to avoid using foul language, etc. I agree. As for the comment that IDSA takes Lyme disease very seriously, I beg to differ. My two children's pediatrician followed the IDSA guidelines when I insisted they be tested for Lyme since they were having joint pain, cognitive issues, bone-crushing fatigue (could no longer do cheer leading, softball, track, soccer, and eventually could do little but lie on the couch). The pediatrician did what she learned from the IDSA: she ordered the ELISA test. The results: negative. I didn't know anything then, so of course I believed my dear sweet children didn't have Lyme. We should not have to do our own research to discover that better testing and diagnosis and treatment are available, usually long after our loved ones have deteriorated to where their lives are devastated. We trust our local doctors to take care of us, and they trust IDSA to provide them with the latest, most accurate guidelines for them to follow. Please do this for them and for us.

Erica Taylor I want to like just about every comment I'm reading. I am so grateful for my ILADS doc and it scares me deeply to imagine what I would have done without him. I have friends who were so sick and can now manage their lives. If it wasn't for these docs who see Lyme and co-infections as a clincial diagnosis, and believe in CHRONIC tick-borne illnesses, many of us in this community would be cripled or dead. I hope that one day the IDSA and medical establishment that has gone after these docs will see the blood on their hands and admit their wrongdoing. How can you allow people to suffer? Open your eyes, change your rules, and start giving a damn about the human lives profoundly affected by chronic Lyme and co-infections.

Sheri Souch I would like to point out as well, IDSA, that there are many comments on here about people who had the bull's eye rash, but tested negative and yet recovered (or improved) with long-term antibiotic treatment. If you are in the business of healing patients, then you need to listen to them. If your guidelines are not working (as is obviously the case,) and if you are an honest Society, then you should change those guidelines to match reality. Why has this not happened?

Sheri Souch IDSA, you need to re-assure Chronic Lyme sufferers that they are being listened to.

Lauren Grace I can only echo the sentiments that others have posted here. I have suffered the devastating effects of Lyme disease for 6 years. Most of my 20's were mired in illness, doctors appointments and medical debt. Chronic Lyme exists - but we don't need to convince you of that - you already know. Why else would you (The IDSA) spend 30-plus years and untold amounts of money researching and defending the position that Lyme disease is a "rare", "hard to catch" and "easy to treat" illness? Why would you appointment some of the best and brightest from the EIS to oversee all things Lyme if Lyme "isn't a big deal"?

No need to answer my questions - my questions answer themselves. I personally don't expect you to change your stance anytime soon, or ever for that matter. You will continue put out flawed scientific studies and control all things Lyme. But do you know what you cannot control? The voice and the spirit of the Lyme community. We will continue to fight even when all seems lost. We are overcomers and we will prevail...

Josh Cutler Infectious Diseases Society of America I though you were encouraging open talks.

"IDSA wants to encourage open dialog" Wouldn't that include you responding to the posts with something other than a generic response. I don't see anyone attack you or your doc's just stating facts.

John Coughlin IDSA please understand all these comments are coming from a lot of pain and suffering.. We have peer reviewed articles from professionals like yourselves that say congenital Lyme happens. I been sick since 1999 and have talked to thousands, yes thousands online and some with whole families infected with Lyme. Some were told ADHD and found Babesia in the kids blood from the Lyme tick bite, countless other stories i can tell that would fill up a hundred pages full of sick patients like myself that found out the hard way that i have Late Stage Lyme.. All we are asking is to look and see all these misdiagnoses and come up with a better plan to screen those properly to who have all the symptoms of Lyme and don't just tell CFS, Fibro etc.. when it was Lyme that was killing me not anything else.. thanks for listening...

Angie Bristow I don't have Lyme, but Rocky Mountain Spotted Fever. You know, the other tick-borne illness that doesn't exist in the medical world; only in my head! Please stop treating us like we a are carzy! We are not crazy, but YOU are making us crazy with your outdated, "cave man"-like thinking, money thristy, souless, sorry excuse for an...go ahead and delete me...we know the real deal! We know that you don't really care, b/c the proof is out for all to see!

Sachiko Yamaguchi Please realize that 28 days of antibiotics is not enough to cure chronic Lyme disease. Most people never see the tick bite so it is hardly caught "early." I have been on oral meds and bicillin shots for 8 months, and now another 7 months of IV. I am paying $$$ since insurance will not cover this due to your Lyme guidelines. The IV has actually helped me so much to regain strength, energy, and most of all mimimize my pain symptoms. so it DOES work. My main issue however is the inaccurate testing and we need to not dismiss these false negatives because too many patients in this country are going misdiagnosed and have a poor quality of life.

Josh Cutler EVERYONE take multiple screen shots of your posts and this entire thread. Make note of what they delete. I am sure with all these people we can reach a paper or major news org and send this to them. Pretty crazy all these people are being ignored and comments being deleted.

Pamela Robertson IDSA takes Lyme serious?? IDSA won't take fowl language really, thats what you have to say? People wouldn't have to curse if the IDSA really did take Lyme serious. It truley is a cover up and how you rest at night well not for me to judge everyone answers to there maker. Maybe your eternal damnation will be chronic Lyme or you may have to watch your love one with this who knows. Lets not worry about the cursing IDSA how bout worryin bout a CURE!!!!!!!

Josh Cutler Guys try to let this go viral. Share the link on your page, take screen shots tell all your friends to come view this.

Helen Metaxas Raser Stop the insanity with Lyme Disease! Involve doctors from IDSA and ILADS to come up with real answers, money for research, and awareness. This kind of mass suffering can not be allowed to continue!

JoAnn O'Linger I am a scientist, or rather, I WAS a scientist.... Lyme disease has taken my career away from me. I'm in bed about 80% of the time now. Please listen to us!!! Read these comments and take us seriously!

Marti Addis-Goforth I would like an answer, or a statement someone from the IDSA with enough courage to say "Yes, Lyme Disease is Real, from this moment on We will take this Seriously"...The phrase "You won't Get it till You Get it" is so very Real. I want to walk into a Doctor's office and receive a look of acceptance, I pray Doctor's receive Education in Lyme Disease, this should be part of their training as being trained in "Bedside" manner. I am beyond tired of trying to explain everything to others because of the IDSA rules and guidelines. Treating amazing human souls as if we are not worth fighting for. I was working in a juvenile detention center gathering wood to build a fire to make s'mores. I was not thinking at that moment all of this would be part of my world, I was trying to enlighten children...

Ashley Grella The REAL truth about Chronic Lyme disease, which has robbed me of several years of life.

Andrea McLain Fennell The information you (IDSA) sited above is exactly the information we have a problem with. There are MANY intelligent people here. Many doctors, researchers, microbiologists etc. have the scientific evidence you say does not exist. Taking it seriously would mean joining forces with the International Lyme and Associated Diseases foundation. Even in your video on Chronic Lyme there is no talk of the babies being born and testing positive for Lyme. You offer no explanation, no alternatives and NO help. This is not taking anything seriously.

Meredith Lodge When I presented with Late Stage Lyme, the doctor told me he could tell by looking at me I had no other Tick Born Diseases. Is this how you train our doctors? He refused to run a blood test for other tick borne diseases. I tested positive when the blood was run by another doctor. Something needs to change and fast.

Mike Hitch I would like to see a much better acceptance of chronic Lyme and other tick-borne illnesses by IDSA and the AMA and the CDC. "Mainstream" medicine, including a vast majority of ID doctors are waaaaay behind on their acceptance and understanding of this pandemic. Open your eyes and accept the fact that chronic Lyme and TBIs exist and that there must be a revision in how they are treated.

Sachiko Yamaguchi Lyme disease IS an epidemic and needs to be addressed at every conference. I was disappointed to see it was not on the agenda at the Oct 2010 Boston IDSA conference.

Pamela Rocke Acknowledge that Lyme can be chronic; that it is more common than not that one get a tick bite without the bullseye or even knowing they've been bit; that symptoms can take months, years or decades to show up in force; that symptoms are much more varied than you now describe; and most importantly that the same tick bite that transfers Lyme infection also *very* often transfers other infections as well!!! It is unconscionable that I am forced to spend tens of thousands of dollars every year -- out of pocket -- to be treated for a chronic health problem just because for-profit insurance companies, by avoiding coverage, stymie research into creating complete and speedy cures! Ultimately, the current status quo is a terrible drain on our country's economy, costing everyone much more money than insurance companies save by not covering us, and drug companies save by not researching and developing cures and better treatments.

Russell Huxtable As another scientist. I know when I look at 60 odd trials and see a recovery rate of around 70% with short term antibiotics, that when the IDSA says it is 97-99% they either don't own a calculator or there are some 'anti-science ' agendas occuring with this Organisation.

Konnichiwa Onnachan What do I want to see from IDSA in the new year? How about more research done on chronic Lyme and a LOT less sweeping under the rug for those of us who go through pure hell with suffering? I will tell you that I will NOT sit here and allow this disease to take my life, with or without your help! Either get onboard or get out of the way. This is a terrible epidemic and the "mainstream medicine" needs to open their eyes!

Jeanie Hinely "What would you like to see from your society in the coming year?"

a head to head Scientific & Publicized and televised debate between IDSA and ILADS on Lyme disease.

IDSA are you willing to go there? Or will you just delete this comment also?

Courtney Lynn Are you listening IDSA? NOW is the time to address these issues. You cant bury your heads in the sand any longer!

Julie Searcy Anderson Thanks for asking. I would seriously like to see the IDSA stop ignoring the elephant in the room. Chronic Lyme Disease DOES exist and thousands of people are suffering. I was told by an Infectious Disease physician that Chronic Lyme was a "scam", that Lyme doesn't exist in Texas and that I had "something", but she didn't know what. She reasoned away my improvement with long term antibiotics (from another doctor), stating that antibiotics were just an expensive Advil. Really? I have to travel out of state for treatment. Public knowledge and understanding of Chronic Lyme is making great progress recently, thank God, due to public outcry and tireless efforts of many--similar to the history of HIV. I advise that you get your physicians with the program, or at least suggest they acquire more liability insurance, because I predict multiple class action lawsuits arising in the very near future for ignoring, mistreating, crippling and/or killing their patients. Oh, and accurate testing, that isn't from the 70s, would be a great start. Unbelievable.

Annette Sharp IDSA, Please have a more open mind about tick-borne diseases and recognize that it CAN remain in the body after a short round of antibiotics. Example: I was infected and started treatment about 7-8 weeks after tick bites. I was still sick as a dog after 6 weeks of antibiotic therapy! It took 4 months before I was well enough to stop antibiotics, yet I STILL have elbow/knee pain, letter reversal issues, floaters and lip/eye twitches. Please acknowledge that there are unknown factors to the illness that you may possibly be wrong about. Thank you.

Jeanie Hinely I bet a terrabyte is too much and that it will take less than a Gig of Screenshots of deleted comments at the hands of IDSA to portray the true nature of IDSA's attitude towards Lyme Disease.

Miralina Stewart Please change your guidelines, chronic Lyme disease is a very real and serious illness. More research needs to be done and better treatments made available!

Leyla Nakisbendi Get over yourselves! You are just wrong!

Dina Brisentine McAweeney I would like to see a few things answered for me....
1. How can I test CDC Positive for Bb, Bart, Babs, Mycoplasma Pneumoniae, Chlamydia Pneumoniae, Mycoplasma Fermentans & reactivated HHV-6 but be told by non-LLMDs that there is nothing wrong with me?
2. How did I go from being in the military, running a 6 minute mile, to being bedridden?
3. Just exactly who am I trying to get "ATTENTION" from?
4. How does a person put 60 lbs. on in 3 months, then lose 50 lbs. in 7 weeks?
5. How can a ER Dr. tell me he/she can't find anything wrong with me, I just need psychiatric help, when I have a below normal WBC, depleted neutrophils, magnesium & potassium, a fever of 103, below normal TSH (hyper) even though I'm overweight & a BP of 85/51, only to be told I need anxiety medicine.
6. How can my LLMD, in one visit, tell me by doing an ultrasound that I have Intestinal Parasites but 18 non-LLMDs couldn't, including 2 ID Drs? Do you have any idea how disgusting it is to vomit up worms & their eggs out of your mouth!?!?
7. Why is it my 2 dogs are treated with more respect & compassion at their freakin' Vet, than I am at my PCP office?
8. How come my dogs Vet can run a LD & Co. test at his office & get an accurate result in 10 minutes but PCP's (not even LLMDs) can't?
9. Why is it that after months of pulsing ABXs & Antivirals (along with several supplements) I am finally starting to do/feel better, I mean, considering the fact that there is nothing wrong with me?
10. And last but not least, how can the IDSA & the Drs. who follow their guidelines sleep at night knowing that a simple, $10 bottle of ABX can relieve so much pain & suffering in a fellow, human being? Do you all have any compassion at all?!?

Meo Doyne Everything as written above. You really need to help us patients out with better education and guidelines. People are sick and dying without proper care and attention because of the guidelines you stuck us with years ago...

Thomas Lee Dunlap clinical trials comprised of long-term and/or chronic test subjects

Debby Matthews WOW!!!! IDSA.....You asked a question.....How do you feel about the responses??? Are you really listening???? DO YOU HEAR THESE PEOPLE?????????? REAL People who are really sick!!!!!! Action speaks louder than words....How about some ACTION!!!!!!

Dolores Claesson Hello IDSA ! Lyme disease is such a misnomer and should instead be called a multi factorial illness encompassing bacterial, protozoal, fungal, parasitical, viral infections and should be analyzed to see what the toxic soup of pathogens each and every one of us has gotten from these zoonotic vectors. The average IDSA physician is clueless as to these pathogens and we would be better served by seeing our local veterinarians ! Something needs to be done to educate these physicians if that is even possible ? Most do not seem to be able to read/comprehend research.

Karen Schlosberg Please acknowledge the long-term problems that many Lyme Disease patients experience, and CHANGE YOUR PROTOCOL. Whether it's Chronic Lyme or post-Lyme, many of us are still affected Lyme and have a very hard time finding AND affording quality health care.

Hallie Richwine Let's get tweeting - make this a trending topic!

Kathleen O'Connell I've contacted a high profile attorney, Erin Brokovitch a few times with regard to IDSA's continuing denial that Chronic or Late Stage Lyme disease is a devistating multi-faceted disease. I think I will copy this thread and send it along to her..Keep the responses coming and send this link to your local congress person as well.

Timothy Grey COMPLETE rescinding of current Lyme Disease diagnostic and treatment guidelines. The current guidelines are in no way designed to benefit existing and future patients. Furthermore the guidelines are constructed in a manner that allows patients to be misdiagnosed in a fatal manner -- Amyotrophic lateral sclerosis, which there is no cure, only palliative care until death. This is not only inhumane, immoral and outside the bounds of the Hippocratic oath but soon will be prosecutable as negligent homicide.

The shame and negative publicity this will bring to the IDSA can be completely avoided by a review of the actions of the few that have negotiated underhanded back-room deals to attain patents and push vaccines through FDA approval.
Don't allow the actions, of a few people, destroy the reputation of the IDSA.

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Tim Grey,
Producer/Director, Under the Eightball

Jennifer Bays Toombs Wow, lots of posts here. Wonder if the IDSA gets this many posts on any OTHER issue???

Dolores Claesson Guidelines ? what guidelines ? No IDSA doc with a brain looks at them !!!!

Pauline Yuhas Mariano I'd like it if you'd get real and update your guidelines so the insurance companies would stop using them as an excuse to deny coverage for treatment!! Everything you have done has hurt thousands of people suffering with Chronic Lyme and yet you continue to deny the existence. You are doctors who took an oath to help patients and yet everything you have done has continued to make our lives more difficult. Where is your compassion and willingness to care for patients? Are you all so intent on just making money that you have forgotten why you became doctors in the first place?

Infectiously Optimistic Last year, a number of writers came together to write a series entitled "My Lyme Disease is Not The IDSA Lyme Disease". Personally, I believe that stories and the account of our experiences speak louder than anger and frustration. Each story shared illustrated the pain, suffering, and debilitation of those who are struggling with Lyme Disease. Yet, each story also shows the courage, strength, and endurance required to keep fighting. I believe that this is a far more effective way to honor the truth, rather than commenting out of frustration and ire. Please see the bottom of the following article to find additional stories and posts.

Birgit Jürschik-Busbach Allow your Lyme Guidelines more flexibility, depending on the patient's response to therapeutic intervention not based on a strict 28-days-of-abx-is enough-scheme!
Primum non nocere!

Greetings from another chronic Lyme sufferer from Germany!

You know that most of the MDs worldwide diagnose and treat LD based on IDSA-Recommendations, so do German physicians.

Yvonne Forey Just one answer off you guys would be good..SURELY you can't ignore all these people pleading.....ANSWER US!

Valarie Murphy So many responses so far, all basically saying the same thing. IDSA, what you can do for us is to "get it." Someone who never got diagnosed and treated, or inadequately treated, may very well be suffering something beyond the "aches and pains" of aging.

I am shocked that you don't understand how Lyme and co-infections deregulate systems - heart, endocrine, joint, brain, etc. Perhaps if you studied that, you would get in touch with appropriate treatment.

Tracy Poland More education for all the Dr's who are turning a blind eye to all the sick people coming thru their office's,crying and pleading for help,and yet all they get are pills,misdiagnoses,and turned away after years and years of sickness,only to be told their Lyme test was negative if they can even talk their Dr into giving them one. I also want to see the testing perfected so the Dr's can start taking us serious.....it would save insurance companies millions of dollars to get diagnosed to begin with and save Lyme sufferers years of ill health,and unnecessary grief........

Stephanie Hanks Edelen Please start taking Lyme disease seriously. My friend is currently taking her daughter, who has Lyme, two states away for treatment. People have had to refinance their homes, get 2nd jobs, and travel out of state to get decent treatment for Lyme. I was with them at a doctor appointment in their home state, that doctor basically told her that she was doing the wrong thing by seeking medical treatment for Lyme from a doctor, who recognizes Lyme, in another state. It was obvious that he didn't believe Lyme was real. He even lied about going out and washing his hands (with a sink two feet away) so that he could look up the Lyme doctor on the computer. We could see his computer screen from where we sat waiting. This disease has taken the active life away from a beautiful 17 year old girl. She can no longer take part in all the church and school activities that she used to be involved in. I was shocked to find out that it was so difficult to get treatment for this disease. Please do something soon to help these people that are suffering from Lyme.

Debby Matthews Apparently.... As we suspect anyways...They are NOT listening!!! How about whoever is sitting there deleting posts & blocking people SPEAK....Address some of these concerns....I'M LISTENING!!!!!

Michael Parent Thank you for taking the time to ask this question. My concern, like so many others is that of dealing with tick borne infectious diseases. Clearly differing points of view on whether or not persistent infection with borrelia burgdorferi remains contentious. My issue however is not as contentious, but does still involve tick-borne infectious disease. Clearly the scientific community has continued to find new pathogens -- as is so evident lately with new discoveries, some of which may be responsible for why patients with ongoing illness after treating Lyme Disease may be one of the factors that divides the medical community from patient advocacy groups.

It is important to consider investigating the study of ticks and to search for whether or not infectious diseases may have developed a symbiotic relationship, having evolved within ticks over such an extensive time period, which may allow a "combination" co-morbid illness to develop leading to persistent illness post-antibiotics. Repeat: We need studies on patients with multiple tick born diseases, to see if the pattern diverges away from a typical picture to that of a much more complex or difficult to treat pattern. So, I hope the IDSA will encourage and support investigation in this area.

Susan Swinson Williams Ditto... stop making Lyme Disease about politics and put the choices back into the hands of the patients who suffer and doctors that treat them.

Patricia Hetrick 3 years, 8 months and 2 weeks of aggressive multi antibiotic treatment has finally brought me back to life. This treatment is in direct violation of the IDSA treatment guidelines but without seeking further treatment I know I would not be here. I would like to see a respected organization like the IDSA earn that respect by making all of the information available to doctors and patients so that more people would have the opportunity to decide on a course of treatment that could save their lives.

Michelle Murphy I have suffered since approx. 1997 till present with chronic Lyme disease and persistant babesia duncani. In the beginning no one believed me. In 2002, I was tx'd x 3 yrs with oral, iv and injectable abx's. some improvement but not "cured". I now am disabled. I was an Rn but can no longer function in that capacity. I am PCR pos. for B. burgdorfori and pos for bab. d. and am receiving treatment by an LLMD. I have to travel out of state and pay out of pocket for treatment. Thanks to the IDSA guidelines no Dr. will treat CLD here. I have late neurological Lyme with mild encephalopathy.

I have done a lot of my own peer reviewed medical research and have found things to be very different from what your guidelines are saying. Why do you close your eyes to this research? Why do you choose not to believe us? Are abx addictive? NO. Do I like being on them? NO. But I need to get better. Kids with acne get more effective treatment than Lyme pts." Where is the death toll from acne? Why don't we hold dermatologists to 2 weeks of tetracycline? And if infections are so easily "cured" by abx, why isn't a simple skin infection like pimples "cured" in 2 weeks? Surely an intracellular infection of the brain or other organs and tissues are more serious than acne. So why are we being told that 28 days of an abx is all a Lyme or Lyme encephalitis pt. needs?" I could go on and on and on.......

Carrie Garman money and greed shouldn't have anything to do with treating a patient that is very ill!!! read the bible, greed and money = EVIL

Kristin Ahles I want more sensitive & accurate testing ASAP! Too many sick people are slipping through the cracks. Trust me if there weren't so many false negatives, you'd have thousands of people commenting on this thread, not merely hundreds. Secondly acknowledge that Chronic Lyme DOES exist!

Dan Thoms Somewhere an intern just got fired for posting this status.

Gayle Link I was misdiagnosed for 15+ years: arthritis, blepheritis, chronic fatigue syndrome, fibromyalgia, and of course the look from doctors that I was making it all up. I went from being an athlete, life of the party and all around high-energy human to a lump on the couch. Finally another Lyme patient recognized my symptoms and encouraged me to get properly tested. I had not only Lyme disease, but also babesia and bartonella along with 4 chronic viral infections. I am thankful everyday for ILADS doctors who saved my life. After being sick for years, I am living my life again and running a hyperbaric clinic so I can help others. Please stop denying that chronic Lyme disease exists and spend your efforts on better testing, diagnosis and treatment!

Debbie Thompson First, do no more harm.

Karla Lehtonen My daughter was allowed to develop late-stage treatment-resistant chronic Lyme disease confounded by multiple co-infections, by ID specialists and primary care doctors who swore by and believed in the IDSA Lyme treatment guidelines. My daughter who has now had two live with chronic illness for years, was crying this morning because she can't think clearly, can't write, and doesn't feel like she will be able to back to even part-time school attendance now that her Christmas vacation is over.

From the IDSA, I'd like an admission of negligence and a financial settlement to pay for my daughter's ongoing medical expenses and poor of quality of life. Stop the persecution of ILADS treating physicians and include them in the design and implementation of new clinical trials. Support clinical trials exploring promising alternative treatments such as hyperthermia for chronic Lyme patients. Support the development and use of better diagnostic tests.

I would like the IDSA to make an honest assessment of their Lyme treatment guidelines, including all scientific points of view and that of the ILADS physicians many of whom have the experience of treating thousands of chronic Lyme patients.

Some of the key points that need to be re-examines in the current treatment guidelines include: recognition of the severity of symptoms in chronic Lyme patients, valuation of patient values and need for quality of life in treatment decisions, elimination of strong recommendations that are not supported by strong science, allowing clinical discretion in basing length of treatment on clinical response rather than set periods of time, recognition that long-term antibiotic treatment may necessary for many patients with chronic Lyme disease, an honest assessment of the high false-negative rates of the two-tier testing regimen in all stages of the illness, acceptance of subjective symptoms in the definition of the disease, recognition of the growing body of evidence supporting persistence of infection after short-term antibiotic treatment, a highly critical look at the actual failure rates in existing studies advocating short-term antibiotic use, recognition of the increasing prevalence of Lyme encephalopathy, as well as the development of effective diagnosis and treatment regimes for encephalopathy.

Courtney Lynn Please everyone start "liking" as many comments as possible. This gives facebook more attention to this post if they see its blowing up fast. Thanks.

Faith Williamson Is ignorance truly bliss, IDSA? Certainly must be as I see not one single response to our 400+ comments. Hmmm...karma has a funny way of catching up with you....

> **Joy JustJoy** *I would like to see the IDSA abolish their current flawed and corrupt Lyme disease guidelines. How can such a small core group carry so much weight? Something is very wrong with this picture and this needs to be investigated at the highest level! The level of human suffering that the IDSA has caused is astronomical and they need to be held accountable. Never in my life would I have ever thought I'd be in a battle for my life up against a tirade of injustice. Look at ALL of these posts! Are you proud? You should hang your heads in shame.*
>
> *-Joy Mandrell Burdge, Testified on behalf of PA HouseBill 272, August 2011*

Louis Ciavolella Please take another look at the testing and treatment guidelines for Lyme Disease. Many people are suffering because of the lack of adequate diagnosis and treatment.

Dawn Marie Kean Wilson
Thank you for posting this question to the public. I have Lyme Disease that went un/misdiagnosed for about a decade due to
1) Lack of knowledge and education among the many physicians I saw and
2) Lack of ELISA and PCR testing accuracy. It was only after a judicious specialist tested me for Babesia duncani, which came back positive, that Lyme was suspected.

I would kindly but firmly implore you to revisit your Lyme Disease Guidelines, as both diagnostic and treatment suggestions truly need revision.

Kathryn Richards LYME stole the lives of myself and 5 children, six of us taking meds THAT are helping, costing me several thousands of dollars out of pocket for a disease that you say does not exist. We are housebound and desperate for real help.

Dolores Claesson Hey if you want research please friend me on Facebook.

Carrie Dyer I'd like to see Doctors allowed to treat Lyme Disease in accordance with their knowledge...not based on what the ISDA deems appropriate. My husband has suffered (and, in turn, we have suffered) with Lyme Disease for over 17 years. DO NOT tell me that chronic Lyme doesn't exist. DO NOT tell me that Lyme can be treated with a short dose of oral antibiotics. DO NOT shun the rapidly growing community of Lyme Disease sufferers.

Sally Egger Please take the time to read Ritchie Shoemaker's work on Chronic Lyme. So many with this condition are suffering due to their hereditary inability to eliminate the neurotoxic products produced by Lyme disease. Every person with chronic Lyme should test their home for mold as it could be preventing their recovery.

Dolores Claesson IDSA this is how dialogue is spelled and therein lies the problem !!

Shelly Bachman Garrison You need to recognize LYME as an infectious disease and educate the public and insurance companies so people can receive proper treatment. These people are suffering, and NOT from mental illness as many doctors would like to believe.

Hallie Richwine 119 screenshots to this point of the thread.

Rob Cotter There has to be a moral imperative to deal with Chronic Lyme and co-infections. An honest evaluation that avoids Big Pharma and insurance profit motives. Lyme is costing this country Trillions in lost productivity but more importantly its costing the lives of all family members.

Sally Marasco I'd like to see a safe, effective Lyme disease vaccine for humans and dogs.

Pamela Rocke Oh, one more thing -- please remove all conflict-of-interest associations amongst your board of directors. You all may have the most wonderful of intentions, but having financial or other ties to the insurance and drug companies creates that slippery slope we all fear, the one we are half-way down before we realize it. And at best, it creates the appearance of a conflict of interest that prevents the group from being effective.

Thora Graves The Infectious Diseases Society needs to accept chronic Lyme disease like any other chronic Infectious Disease.

Kathryn Richards my tick bite was in 1976 and I was diagnosed this year. 5 kids with problems since birth have all tested positive and are slowly improving with treatment. WE ARE NOT MAKING THIS UP - 35 years is a long time to be sick with something abx could have helped and saved all my children from infection if properly diagnosed and treated when it happened. There are thousands of stories JUST like this. It is an epidemic but we are too tired and sick to raise hell, yet.

Debby Matthews My last post....DELETED!!!! Seriously? Is this how you do things????....Hmmmm....Waste of time......

Denise StGermain http://whatisLyme.com/rest-in-peace/

Rest In Peace
whatisLyme.com
People who have died of Lyme Disease

Donna Zukaitis Falcone http://whatisLyme.com/rest-in-peace/

Dawn E. Perry I know many people who have suffered from Lyme or are suffering still from it, yet it is barely recognized. Lyme disease needs to be the #1 PASSION of IDSA.

Debby Matthews Nobody with the IDSA is listening....They have their own agenda.....It has nothing to do with any of us and our disease or concerns!

Joy JustJoy I would like to see the IDSA abolish their current flawed and corrupt Lyme disease guidelines. How can such a small core group carry so much weight? Something is very wrong with this picture and this needs to be investigated at the highest level! The level of human suffering that the IDSA has caused is astronomical and they need to be held accountable. Never in my life would I have ever thought I'd be in a battle for my life up against a tirade of injustice. Look at ALL of these posts! Are you proud? You should hang your heads in shame.

Mandy Knowles Let the doctors treat how they think is the best for our kids...and pay for the treatments needed!!!!!

Kimberly Cerrudo Lose the conflicts of interest. Open your eyes to the science that Chronic Lyme exists. Recognize the seriousness of the disease and epidemic. Your current guidelines are causing irreparable damage to patients. Lives are forever changed, some lost because of them. Please remember your oath to do no harm.

Mary Ann Mazzarella 6 yrs w/ Lyme and wasted a lot of time and money on Dr's that don't have a clue. The worst was the Infectious Disease dr, which should have been the best. Your guidelines are outdated and incorrect. Dr's that care, understand and treat patients with chronic Lyme should be writing the guidleines along with people who have it. Please do something about this, we need your help.

Adrienne L Ritchie A response to any of these requests would be miraculous in and of itself!

Ashley Eduvigen Address Lyme disease and chronic Lyme disease, stop denying treatment and insurance coverage, and start saving lives!

Valarie Murphy [Hundreds of] comments so far, and they all say basically the same thing.

Valarie Murphy Oh, another thing - stop your participants from testifying against Lyme docs. Your participation in that persecution makes IDSA look very, very bad.

Elaine Garfield get the truth out about how severe this illness is. People are so debilitated and are dying while another agenda is taking precedence. Human life is the most important agenda there can be. Please remember how many illnesses were judged wrongly and people are still dying because of the arrogance of the medical establishment. Past time to set ego aside. Do the right and humane thing.

Catherine Collins Well IDSA, you did ask. Now can you listen? Just how accountable are you to the people of your country and the rest of the world who remain sick because of your flawed tick borne diseases guidelines? Medicine and science are not static, hypotheses move with research and experience.Listen and learn from all these patient experiences. Can your "opinions" ever reflect this?

Rob Cloutier Open your eyes to the FACT that there are a lot of people out there suffering from a condition that only a handful of your members (the Lyme guidelines board) are trying to deny exists because insurance companies pay them to. Someday, it may not be today or tomorrow, but enough people are going to be sick that there WILL be national class action lawsuits against that panel - and the longer you stay associated with that panel, the more your organization will be legally in hot water for complicity to the terrible crimes the IDSA Lyme panel has committed. Anyone with half a brain at the head of the IDSA would cut off any connection to the "doctors" on the board (who should be in jail, btw) from the IDSA simply on the means of financial and PR sense - and that's not even touching on the moral side of it. Why would you jeopardize your organization for the sake of 5 -6 corrupt individuals who are making thousands of people suffer?

Have you not noticed that your organization is becoming more and more hotly debated in state legislatures? The proven legal action by the state of CT's attorney General that fiscal indiscretion was committed by the Lyme board? That there are widely respected documentaries airing on PBS that makes your organization look terrible? Do you not have ANY political or PR sense? Cut them free! They can't hide behind the IDSA forever. Think about the rising rates of Lyme every year. Thousands more are being hurt by your panel every year, including some very powerful people. Ticks don't discriminate between the homeless or Senators... You cannot deny knowing how this is going to end up in a litigious environment, and the sooner you dump your Lyme panel, the better for you.

Kimo Bailey The suffering for me and you all has been just crazy, its every day every night – 24/7/365. How can the Dr.s not see this? Professional BLINDERS?

Barbara L. Baker Intelligence freed from greed, freed from big pharma, freed from insurance company lobbyist. Intelligence and compassion. Two qualities completely missing from Lyme reporting.

Victoria Wilguess I'm only 18. I was 13 when I got sick, but 15 when I got really sick. From what? Lyme Disease and co-infections. I've been bedridden, missed high school, and had to travel across the COUNTRY to find a doctor that will even treat me. This year, I want for you to help me. I want to not spend another day hooked up to IVs. This disease has taken 2 organs from me, caused me to go to the ER over 50 times, caused me to get a PICC line and port for IVs, has affected my brain, and has affected every single organ, bone, and joint. And I'm only 18. I want to be able to go to college and become a nurse to help others. So this year, I just want you to help me. But I want you to know that even though Lyme is taking a lot from me, I won't give up or let it stop me. I just need you to tell me this year. I don't want to be sick anymore. I don't want to see any more people get Lyme. That is what I want this year.

Neil McNamara I hear you are deleting posts from Lyme sufferers like myself. Look at all of these posts!! You must change your Lyme guidelines as they are causing the suffering and loss of life for thousands around the world. ILADS are the authority on Lyme and tick bourne disease treatment. Chronic Lyme is making a fool out of the IDSA!! The truth will prevail, and I only hope your board members are held accountable for this genocide they have overseen. I don't know how any of you can sleep at night.

Cathy Glenn Would like to see the horrible truth about this disease told. Would like to see doctors truly educated on how to diagnose and treat correctly. Would like to see insurance pay for treatment just like any other disease. Would like research $$ to.

Wendy Vogt The IDSA should stand for more than I Don't See Anything. You are responsible for an unchecked epidemic. Start being the experts on a disease that is growing faster than AIDS. Start now.

Cathy Glenn (continued from above). Would to see research $$ go to developing DEFINITIVE tests for this disease so people know what they are up against and can make informed choices?

Kiera Farr Someone simply needs to just step up, and really help! can't take much more of this myself.

Melissa Rascio I am asking that the IDSA do their jobs as doctors and get people the help they need. It is extremely silly that I could have a text book case of Lyme Disease and an Infectious Disease Doctor could possibly tell me that after 2 weeks of treatment(my headache, stiff neck and fever) are being caused by "something else" when those same EXACT symptoms are what lead my doctor to test me for Lyme in the first place. This disease can do ALOT more then give you swollen joints! The anger among the people commenting on here is justified. There is evidence being ignored, why?

It is no coincidence that so many of us Chronic Lyme Sufferers get labeled with things like RA, Lupus, MS, ALS to name a few. If there is no cure for Lyme Disease, don't you think we, the ones suffering from it have a right to know?! For many of us, we have been infected most of our lives due to the lack of education when this disease was recognized in this country. Some of us don't even know what it feels like to be healthy. Some of us have gone our entire lives thinking no one understood the pain and weird symptoms we felt. Still to this day, doctors do not understand the disease that most of their sick patients have! I am demanding that research be done on Lyme Disease and its transmission to a fetus in utero. There is no reason why an OBGYN should tell their pregnant patient not to worry about this when there is evidence that proves the transmission of the disease to an unborn baby!

I could go on for days, on why the IDSA is failing at what they are supposed to be experts in. The IDSA does not consist of any experts, by any means. There are thousands of us on the web and we are not going to be quiet. Everyday there are more and more of us who look to the web for answers because we KNOW that what happened in our bodies after Lyme is completely the opposite of what our doctors said would happen. Our doctors made us think we had Lyme Disease, its easily cured and we could move on with our lives. That’s not whets happening!!!!

Many more people will go undiagnosed for years (like myself) until a stressful period in their lives when the disease will be able to tear their bodies apart and they will end up bedridden like the rest. There is no reason why a person should have to find out what they really have by looking on the internet for more people like themselves to see if "they were the only one", only to find out, they were not the only one, there are thousands and thousands of people who are not getting better after 2 weeks of antibiotics. Luckily for myself I found out and got myself to a doctor who could treat me the right way and long enough....thanks to the people here posting comments who ARE educated about this disease. In my eyes, you are not doctors. You are a WASTE to society. Doctors are supposed to help people, they are supposed to keep people from suffering, they are supposed to be honest, they are supposed to cure people when possible.

Stop trying to make money off of our 100 different symptoms and cure us of this ugly disease. STOP ignoring the research and evidence from the ILADS. It was an ILADS doctor who helped myself and many others. Please start thinking outside of what you learned in med school and update yourselves on the new information that is out there. We are loosing hope and all trust in doctors who know nothing about a disease that is growing FASTER THAN AIDS!!!

Cathy Glenn Informed decisions about their healthcare. BASICALLY THE SAME RIGHTS THAT OTHER PEOPLE HAVE IN THIS COUNTRY WHEN THEY ARE FACED WITH AN ILLNESS/DISEASE.

Lark Letchworth I just want medical professionals to be educated in diagnosing and treating tick-borne diseases like Lyme, and the IDSA and CDC to recognize and acknowledge the truths about those treatments, so that no other human has to go through the years of misdiagnosis and mistreatment I did. The IDSA protocols are destroying lives. How shameful. You prioritize pharma money over human lives?

Jessica Slack Open your eyes to the science that Chronic Lyme exists. Recognize the seriousness of the disease and epidemic. It effects a lot of people...I personally know someone going through it, This is very real and you all need to stop trying to hide the facts and man up and DO SOMETHING!!!!!

Karen Friesen Like many other patients, I would like to see the IDSA revise treatment guidelines for Chronic Lyme Disease in 2012.

Valarie Murphy I remember when the doc discovered that h-pylori was causing stomach ulcers. That brave man was treated with great disdain by the medical community. Then he won the Nobel prize.

I have little respect for doctors who are close-minded and treat us with utter contempt. They tried to tell me that being crazy destroyed my knee cartilage.

David Cheney Lyme admission!! Remove politics from your org. and do what you are supposed to do.

Chris Parsley Kodawe I for one used to look up to doctors, as I believe most of us have done in the past. It is now to the point that I have lost all respect for the majority of the medical community. We watch as the health of friends and family deteriorate, yet the doctors do not see it. Best I can tell the majority of doctors are over paid pill pushers with no reguard for human life. I am the parent of a vaccine damaged child. I watched my child change in one day, the day he received his vaccination shots that I was told were harmless by a arrogant self righteous doctor. I have lost a good friend to illness that started the day he was injected with a flu vaccination. The madness has to stop! Most people out there are at the very least wary of these shots and many are witnessing the devastating effects. Something is wrong and the public is becoming informed.

Nicola Seal I would like to see recognition from the IDSA that Lyme disease can persist, and cause a devastating, yet treatable illness. Short courses of antibiotics have been shown in the literature to be completely inadequate for many cases of Lyme. Persistence is proven, we know Lyme can survive short courses of antibiotics, yet the IDSA deny this blatantly obvious fact. Common sense should rule. The thousands who are suffering, and the ones who were cured (like me) with long courses of antibiotics should be listened to.

Theresa Denham Ivanov I would like you to recognize that your society doctors are human not Gods, and train them to act in such a way. As a support leader I have watched patients get bullied, and have watched patients die because the IDSA physicians have a preconceived ideas that this is all in their head, or even worse, that the current trent in grant funding is X, so the patient has X, so that they can get the research $$.. I have had CDC positive patients (multiple tests, mutiple labs including ones you guys use like Stoneybrook, Labcorp) come back with positive tests only to be told its false positive. IDSA physicians need to use the deductive reasoning, rather than wrote book smarts when evaluating patients. Just because I live where you haven’t seen Lyme, doesn’t mean its not here. (in fact I imported hunting dogs from the east coast full of ticks. Is it possible that’s how we got our first exposure?)

Kathy Valimont Schreiber My vote also for Lyme disease and the other tick-transmitted illnesses. There a too many people suffering horribly from under treatment/no treatment of this disease. Regarding evidence, when is a history of Lyme disease and persistent symptoms from masses of people not considered evidence? Are we all imagining it? PLEASE, PLEASE address this.

Lise Sheehan I was told by my pcp when i got bit by a tick in 2007 that since I did not get the rash there was nothing to worry about. Now I can barely function, every year gets worse. You need to run a massive public education effort and advise people to take a precautionary course of antibiotics as soon as they have been bit, especially people who already have chronic illness. I believe that my immune system was unable to muster up a rash, and since so many have immune issues today in our toxic environment, this is probably the norm. Also, I was told there was no point in keeping the tick, which I had for a while. Now I find out my local ag dept at the university does testing every week. But I was told NOT TO WORRY. There is too much conflicting information. Everyone is confused, and thus no one knows what the heck to do. You people need to ACT.

Sam Malone Make this the year that you champion evidence based treatment in borreliosis and neuroborreliosis ...

Wendy Vogt There have been *at least* 1,000+ responses to your question. I see you are deleting huge numbers of them. That tells a story right there... why delete sincere answers to a question you asked?

Ulana Legedza Please recognize chronic Lyme - read Ritchie Shoemaker's book and papers.

Melissa Rascio Oh yes, I just need to add one thing...My infectious Disease Dr Middleton, tested me for co-infections...he left an important one out (I had no idea at the time). Later My ILADS doctor tested me for all co-infections only to find out, Dr. Middleton never tested me for Babesia which is what was still causing my fevers. THIS SHOULD NOT HAPPEN! Once I was treated for the Babesia, my fevers went away.

Not testing someone for a possibly fatal parasite because they dont live in an area where it might be is sickening. Most doctors will not even think to test for co-infections leaving people who may have gotten better if caught fast and treated fast, still sick. Its a joke, and that lack of knowledge from doctors about knew and emerging diseases is ruining many lives.

Stacy Christensen i would like to see corps.gov tell us the truth about Fukushima, Japan http://enenews.com/ ... also, an alternative democrat candidate would be fabulous.

Kim DeSantis Goodwin There are people committing suicide because of the hopelessness your guidelines have caused their lives. The symptom list needs to be real not just the few common symptoms there are hundreds and no two are alike. Making it known the depression, anxiety, personality disorders this illness when infested in your brain causes. It changes people ruins them, their futures, their jobs, their connections with people. I hope one day to get my life back and for everyone suffering to get their lives back. So much damage being caused inside our bodies everyday while there is no cure. Long term antibiotics from a Lyme dr is the only chance at any life but there is no research or knowledge about this to the people who most need to be educated and money needs to be put into a cure. Everyone will get Lyme at this rate. If you lived one day in our shoes maybe you would see the torture you have caused.. you have millions of lives in your hands you can kill us or save us.. at some point you will meet your maker.

Snap Crackle Pop *Please Recognize the Chronic Lyme Disease (and coinfection) Complex! Develop definitive tests (the Dearborne standard SUCKS, Western Blots are iffy and the ELISA is totally useless), be honest about borrelia's persistence in the body and the difficulty of the infection complex seen in many with Lyme, the fact that it is transmitted in utero and breast milk, investigate whether or not is it sexually transmitted like its cousin syphilis, and promote the choice in treatment between doctor and patient - not limiting it to a mere 28 day course of abx at most.*

Snap Crackle Pop Please Recognize the Chronic Lyme Disease (and coinfection) Complex! Develop definitive tests (the Dearborne standard SUCKS, Western Blots are iffy and the ELISA is totally useless), be honest about borrelia's persistence in the body and the difficulty of the infection complex seen in many with Lyme, the fact that it is transmitted in utero and breast milk, investigate whether or not is it sexually transmitted like its cousin syphilis, and promote the choice in treatment between doctor and patient - not limiting it to a mere 28 day course of abx at most.

I got Lyme in NC at 9 or 10. If a doctor had been literate it would have been a simple course of antibiotics. I went undiagnosed and untreated until I was 18 years old, and there is no WAY that a mere 28 days of antibiotics can eradicate such a chronic and pernicious infection. I battled it on and off for nearly 4 years, and am now working on restoring my body because the cause of the aftermath is finally gone. I'm not extremely pro-antibiotic - due to the chronicity of the infection I opted for a natural and herbal antibiotic approach rather than conventional antibiotics. It took a lot of work but I have my life back. I had to think on my own, and totally disregard the deeply flawed IDSA Lyme guidelines - in order to get my health back.

Marge Jaroch Eveland I would like to see the IDSA become Less Judgmental re: those who have been decimated by Lyme disease & the co-infections. I'd like for them to be MORE open-minded, LESS BigPharma owned, MORE compassionate to our sufferings, and LESS likely to tell us that our problems are psychosomatic. "The 'blood' never lies, baby!" (yet my bloodwork was disdained, ignored)..because the Insurance companies don't want to pay. Ie, I'd like for the members of IDSA to possess "more FORTITUDE than what certain governmental "intere$t$" possess.
...The only time I was in true need of "mental health intervention" was when I naively BOUGHT INTO THE IDEA THAT (most, if not all) M.D.s of the C.D.C. WERE TRULY interested AND able re: HELPING ME.

Rita Rhoads Reed IDSA needs to let all doctors know that traditional Lyme tests let out important bands. It would have saved our family suffering children.

Marge Jaroch Eveland ..just sayin' ~ And, thought you might want to know that...in case one of your beloved family members begins,
..."needing a psychiatrist," and "needing psychogenic drugs"
You asked. I answered. Will you listen?

Kimberly Aldrup-Otto I would love love love to see more about Lyme Induced Autism and Treatment for my 3 year old who contracted Lyme from me. As well as, General education to Doctors about Chronic Lyme Disease, adaquate treatment, prolonged treatment, and acknowledge that we are suffering. I was turned away from the local Infectious Disease because I only had 3 positive bands and not 5. So they let an infectious disease person go back into the world.... I contracted Lyme from my ex-husband, maybe check into that and stop denying that it happened by STD. Thank you!

Kimberly Aldrup-Otto Lyme Mom, Sufferer for 9 years, and Advocate.

Melissa Rascio Where are your replies? Shouldn't the IDSA be answering our questions and defending their guidelines? If the guidelines are not flawed, then defend them...

Lydia Niederwerfer Set aside your egos and look and accept all the evidence that shows that the Lyme Disease bacteria can persist after the prescribed outlined treatment guidelines. See that this disease is not “one size fits all” and everyone should be allowed the necessary treatment according to their needs. Let the doctors that know how to treat Lyme disease do what is best for their patients. Do what is best for the patients & open your eyes to the medical evidence that, at times, prolonged treatment does more good than harm. I’m living proof that the RIGHT and PROPER treatment does work with absolutely no lingering symptoms. It takes great strength to show that sometimes we are human and we do make mistakes, but now is the time to do what’s right and help those that don’t fit the “cookie cutter” approach in treating Lyme Disease. Do what’s right and make the necessary guideline modifications that are needed so that the thousands that are continuing to suffer with Post Lyme Syndrome a/k/a chronic Lyme Disease can recover and regain their lives.

Gerald Kimber White For it to take Chronic Lyme Disease seriously.

Andy Abrahams Wilson These comments speak volumes. Do the right thing IDSA: Admit that your Lyme Disease Guidelines are flawed, and facilitate a "Manhattan (Lyme?) Project" to address new ideas and approaches regarding Lyme and other tick-borne diseases. It's time to think outside of the box!

-Andy Abrahams Wilson, Producer/Director, UNDER OUR SKIN http://www.facebook.com/underourskin

Brad J Stewart I would like to take the IDSA for a walk in my woods.

Debra Grasley I'd like to not have to feel ashamed to tell physicians that I had Lyme Disease. I'd like it if the medical profession believed that chronic LD exists. If long-term antibiotics are not effective, well, why not devote some research dollars into finding an effective treatment. Of course, since chronic LD doesn't exist, then please let us know what's wrong with us?

Valerie Mains Wolfer For years I was told I had a poor immune system...then I was diagnosed with CFIDS and told by an ID doc that my level of functioning was below many of his AIDS patients but unfortunately there was no effective treatment for CFIDS yet. I was put on disability and continued to progressively get worse and then finally after numerous inaccurate tests for Lyme, a knowledgeable doctor whispered to me that I needed to see a Lyme literate doctor immediately because I had almost every symptom on the list including brain lesions. Unfortunately, after 30 years of various health issues I found out too late that Lyme was the cause and am not responding to treatment as hoped. To add insult to injury family and friends are repeatedly told Lyme Disease is no big deal or that it doesn't exist by their own doctors. In what world is it no big deal when a person has all of the following: brain lesions, seizures, tremors, inflammation, profound fatigue, flu-like symptoms, compromised immune system, autonomic dysfunction, severe cognitive issues, lymphatic disease, chemical sensitivities, neuropathy, joint deterioration, autoimmune diseases of the thyroid, lungs and cns; relenting joint, muscle and nerve pain and more recently problems detected with the heart, kidneys and liver. No big deal...I think not IDSA!

Jen Marie an accurate, informed, compassionate stance on chronic Lyme - some integrity would be nice.

Kathleen Courtade Collins You say that you want to encourage open dialog, but as a competent practicing medical professional and a survivor of chronic Lyme disease, I feel like a voice crying out in the wilderness. I would like to see Lyme disease treatment guidelines revised. Last year, the IOM said it was essential for medical guidelines to take patient viewpoints into account. The IDSA hasn't done that. Rather, patients are routinely denied appropriate medical care because

IDSA-influenced doctors and insurance providers follow IDSA Lyme treatment guidelines. Lives and families suffer physical, emotional and financial devastation because of these narrow, biased guidelines. I would like to see the IDSA REVISE the Lyme treatment guidelines, including in the discussion patients and the physicians treating them, from BOTH sides of the aisle, not just one treatment perspective. I was blessed with advanced knowledge, insight, access, and was able to pursue prolonged treatment; I've been symptom free for 7 years (after almost years of worsening symptoms). How many others have continued to suffer - or have died - in the meantime, because of ill-advised treatment protocols? "Above all, DO NO HARM..."

Jon Lallement Get out of the pocket of the insurance companies, and walk in our shoes

Valerie Mains Wolfer Testimony that so many of us can relate to -http://www.youtube.com/watch?v=rlwBuFAI

Beverly Burgess I was diagnosed 3 years ago with Erlichiosis and received 28 days of antibiotics. 6 months later I was positive for Babesia. 2 years later I am positive for Lyme and Bartonella.I now have brain lesions, cardiac damage, vision loss and somedays can't remember my name. I walk with a cane and had to give up my 20 year nursing career to go on disability.

Thankfully I found a LLMD to treat me but there has much damage been done. I was called crazy for 3 years and told I had fibromyalgia. We need better testing, more LLMD's, more public education on Lyme, better access to meds, and insurance to cover the staggering medical bills. The CDC recommendations are shameful and hurting many. I am so angry and disgusted how patients are treated.

Jennifer Breault How long will they close their eyes to this awful sometimes fatal disease?? Have some compassion, and how about morals!!!

Cheryl Henderson-Brill My husband has had undiagnosed Lyme for 15 yrs until last year when we finally found a dr to treat him. Because of the IDSA beliefs, he has limited care. We both want to him to feel like normal again. Lyme and your beliefs have stolen 11 yrs from our marriage and his enjoyment of life. You need to stand up and recognize chronic Lyme, because IT DOES EXIST! I see it everyday! He and countless other patients have SUFFERED LONG ENOUGH! Change your thoughts! How much proof do you need?

Małgorzata Szkutnik I wish all IDSA members get bitten by infected ticks and have "post-Lyme syndrome".

Renae DeGray Mathe Please address Lyme Disease and Chronic Lyme Disease, stop denying treatment and insurance coverage, and save lives! There is absolutely no valid reason not to.

Kim Swann-King I am in the process of helping to take care of my mother who DOES have Chronic Lyme Disease. If only a doctor had known her symptoms could have been related to Lyme's disease and run the test, treated her then all the neurological problems that she is having right now would not be happening. Open your eyes IDSA- this disease is REAL and NOT in peoples heads. I wish you could be standing in my shoes right now- watching how this disease is destroying my mother's life and breaking my heart.

Valerie Mains Wolfer
http://www.youtube.com/watch?v=JpPFKpFXmQ&feature=player_embedded

Valarie Murphy IDSA's abuse of Lyme victims is going viral:
http://www.Lymedisease.org/news/touchedbyLyme/idsaviral.html

Jo-Ann Colburn I really think that you all should re-read this oath (I SWEAR in the presence of the Almighty and before my family, my teachers and my peers that according to my ability and judgment I will keep this Oath and Stipulation.

TO RECKON all who have taught me this art equally dear to me as my parents and in the same spirit and dedication to impart a knowledge of the art of medicine to others. I will continue with diligence to keep abreast of advances in medicine. I will treat without exception all who seek my ministrations, so long as the treatment of others is not compromised thereby, and I will seek the counsel of particularly skilled physicians where indicated for the benefit of my patient.

I WILL FOLLOW that method of treatment which according to my ability and judgment, I consider for the benefit of my patient and abstain from whatever is harmful or mischievous. I will neither prescribe nor administer a lethal dose of medicine to any patient even if asked nor counsel any such thing nor perform the utmost respect for every human life from fertilization to natural death and reject abortion that deliberately takes a unique human life.

WITH PURITY, HOLINESS AND BENEFICENCE I will pass my life and practice my art. Except for the prudent correction of an imminent danger, I will neither treat any patient nor carry out any research on any human being without the valid informed consent of the subject or the appropriate legal protector thereof, understanding that research must have as its purpose the furtherance of the health of that individual. Into whatever patient setting I enter, I will go for the benefit of the sick and will abstain from every voluntary act of mischief or corruption and further from the seduction of any patient.

WHATEVER IN CONNECTION with my professional practice or not in connection with it I may see or hear in the lives of my patients which ought not be spoken abroad, I will not divulge, reckoning that all such should be kept secret.

WHILE I CONTINUE to keep this Oath unviolated may it be granted to me to enjoy life and the practice of the art and science of medicine with the blessing of the Almighty and respected by my peers and society, but should I trespass and violate this Oath, may the reverse by my lot) that you took and think about how negatively the decisions that you have made have impacted so many people.

Lindsey Galligan Please recognize Chronic Lyme! coming from a year sufferer.

Diane Biel Look into my girls eyes and tell them they are not sick....because the pain they have from TBD's are killing them and myself....please do something about this...please...

Dawn Dumas Larson I was diagnosed with Lyme only 2 months ago. I have had this disease for approx. 20 years. Dr. after Dr. would not confirm the illness despite blood work and clinical criteria, because I did not remember a tick bite or rash.

Andy Abrahams Wilson *These comments speak volumes. Do the right thing IDSA: Admit that your Lyme Disease Guidelines are flawed, and facilitate a "Manhattan (Lyme?) Project" to address new ideas and approaches regarding Lyme and other tick-borne diseases. It's time to think outside of the box!*

-Andy Abrahams Wilson,
Producer/Director, UNDER OUR SKIN

Now I am taking appropriate medication and along with dietary adjustments for the first time in a long time I can function through the day without crashing.
I would like to see revisions to the guidelines and better education so that others can avoid needless suffering.

Julianne Zhou Can I get back the 4 years I lost as doctors failed to effectively treat my sero-positive Lyme disease using your guidelines? Or would it be more effective to wish for more doctors like the one who finally saved my life by being willing to think outside the box you put them in?

Tapp Francke Ingolia I would like to see the position taken on Lyme and chronic Lyme changed. It is clear that Lyme disease is a much bigger issue then was originally thought. It is time to wake up and see what is really happening. It is shameful that so many people are suffering when they can be helped. Relax the guidelines to include co-infections and non CDC positive cases of Lyme. More doctors need to be properly educated on Lyme. It is an epidemic now and needs to be dealt with as such.

Cheryl Henderson-Brill With all the info and books I have read so far...I feel like I'm more of an expert than the IDSA panel is!

Linda Christopherson Linquist I would like to see an end to corrupt Doctors who hoard research for profit, and make decisions with drug and insurance companies in their back pocket.

Artur Dudka Start taking Lyme disease seriously...

Jeff Slawson I would like to see the IDSA admit they are wrong about Lyme. I would like to see them admit that they KNEW they were wrong and did nothing. I would like to see the IDSA Doctor that diagnosed me with PTSD and told me to "stop practicing voodoo and I will get healthy" brought up on charges.

Kaethe Mitchell Dear IDSA, when our children make a mistake, we parents allow them the opportunity to learn from it, stop lying about it, and move forward. Each of us here is allowing the IDSA to do that now.

We're not looking for revenge or a chance to say "I told you so". There is way too much at stake for that pettiness. People in every state of the US are becoming infected with Lyme and many other tick-borne diseases and are going undiagnosed and un/under treated. It's time to learn, quit lying, and move on. I know my kids would be disabled by now if I had listened to all the doctors and specialists who wanted me to follow their advice, gleaned from the IDSA guidelines. In 2012, please resolve to change them.

Suzie Lacroix I would like to see the IDSA revise treatment guidelines for Chronic Lyme Disease in 2012

Sheila Saccone I was diagnosed only 6 months ago. Without health insurance and with the current thinking on what this disease is and does, I am doomed to a dismal future. Please help us get the help we need.

Rachel Bechler Green Recognition of Chronic Lyme Disease and real solutions for treatment and better testing.

Jennifer Yin RECOGNIZE CHRONIC LYME DISEASE. Current treatment protocol according to the IDSA guidelines are extremely faulty! I was treated considerably early for Lyme (35 days into infection), I did 6 months of antibiotics and a ton of herbal medications. It's been a year and a half now, I am soo much better than before treatment and continue to improve on alternative treatment, but I'm still not 100% back to normal. This disease is living hell.

Barbara Berselli Murphy Lyme Disease - please please please help all those who suffer needlessly it effects far too many people everyday

Randy Garvin Printed posts. Suggest you do the same!!! Sure "somehow" post got lost or deleted by the IDSA and no one mentioned chronic Lyme. 500+ posts and "likes" in just 24 hours! Yet still the directors will do nothing.

Karen Williamson-Keller Make it a forced priority to MANDATE LYME EDUCATION TO ALL PRIMARY CARE PHYSICIANS. My peds office is totally clueless!!! We are still trying to get a diagnosis after 9 months. Our state insurance won't allow us to see a specialist without referrals and my ped said no rash, no Lyme. Wtf? So my child lives in chronic pain :(. Please, acknowledge the education and standards must be looked at once more and re regulated.

> **Diane Biel** *Look into my girls eyes and tell them they are not sick....because the pain they have from TBD's are killing them and myself....please do something about this...please...*

Donna Zukaitis Falcone IDSA GOING VIRAL!! bet the IDSA wishes it was for doing something heroic and benevolent!
http://www.Lymedisease.org/news/touchedbyLyme/idsaviral.html

Jo Anne Pettit Recognize Chronic Lyme Disease and listen to the people and doctors that know what has helped...for me it was ILADS and their treatment guidelines that saved my life!!

Kortni Gehri I'd like to see chronic Lyme disease recognized and medical doctors taught about it!

Angie Yoho Robertson Be openly honest that chronic Lyme exists, give patients fair treatment and stop the suffering of these people. Suffering for for over 8 years now!

Angela Castle 2012 is the year the Lyme disease guidelines must change!! The evidence is quite clear that chronic Lyme disease DOES exist, that in many cases, long-term treatment with antibiotics clearly works and greatly improves lives of those suffering. Please wake up to this epidemic and do the right thing! This immense problem needs prompt action and must include revised guidelines, research, and education of doctors on a large scale.

Whitney Janas CHANGE YOUR GUIDELINES. In refusing to do so, you are responsible for teaching practitioners everywhere to perpetuate the widespread belief that WE ARE NOT SICK. We are real people suffering with a very real illness and the fact that you do not understand it does not mean you can say it doesn't exist. STEP UP. Stop writing off what you don't understand as nonsense, and tackle it head on! You've got the power and the resources. Instead of abusing it at the expense of the lives of GOOD PEOPLE, seek out ANSWERS to this confusing epidemic. ADMIT that it is a VERY serious epidemic! Your actions up until now have been the equivalent of sticking your fingers in your ears and saying, "La la la I can't hear you!".

You've tried to ignore us, but now you see that you can't. This problem cannot be swept under the rug - ignoring a problem of this magnitude only provides a disservice to us all and serves to discredit the entire medicical profession. “I will use those dietary regimens which will benefit my patients according to my greatest ability and judgment, and I will do no harm or injustice to them...So long as I maintain this Oath faithfully and without corruption, may it be granted to me to partake of life fully and the practice of my art, gaining the respect of all men for all time. However, should I transgress this Oath and violate it, may the opposite be my fate.” Does this sound familiar???

Ryan Whitwood Recognize the existence of Chronic Lyme Disease and its proper treatment. Don't leave those infected suffering because of your closed mindedness and ignorance of facts. These people did not choose to get sick and shouldn't be treated like attention seekers, but as patients with a real illness that has left them debilitated. We would love to support "your" society, but until you support Chronic Lyme Disease patients it will never be "our" society.

Kimberly Aldrup-Otto Don't you find it funny that the comments are regarding Lyme Disease out of ALLLL the infectious Diseases. OPEN YOUR EYES AND CLOSE YOUR POCKETS! ♥

Thomas Kistler Revise treatment guidelines to actually help us and make it easier to get treatment. Recognize Lyme is almost everywhere and anyone can get it. Most of all get together and find a decent cure for people so we don't have to waste our lives away in pain. So we actually have a life and can contribute to society.

Brianna Brackett Recognize Chronic Lyme Disease! Listen to those who have suffered.

Paul Woodson Like many others, I would like to see the Lyme diagnosis and treatment guidelines revised.

Colette Prcevich You need to re-visit the Lyme disease guidelines. The science is published that chronic Lyme disease does exist and that persistant infection persists despite short term antibiotics. The science is there that it is passed congenitally from mother to child. The science is there that one usually also has co-infections. Would you like me to provide the links for you to these scientific studies? Oh wait, you already KNOW and have seen them but choose instead to deny people their well being to fill your own pockets with money!

I live in Canada and our health system adopted your flawed guidelines in 2006 and thousands upon thousands of people go mis-diagnosed every day. I have had to travel and pay out of my own pocket for medical costs for treatment and we supposedly have free health care. I have passed this horrible disease to my children through birth and also my oldest was bitten in 2008 and denied treatment even though he had a bulls eye rash. I am fortunate enough that we are getting treatment for myself and our three children and with long term antibiotics, we ARE getting better. Please wake up!!!!!!!!

Kimberly Aldrup-Otto Insurance doesn't cover our disease because of the guidelines, they don't have to. So we are suffering in more ways than you could ever imagine.

Kaitlin Wilson Blackburn Recognize Lyme and related tick borne illnesses as the serious, life changing afflictions they are. As someone who suffers daily from Lyme, it is heartbreaking to feel that conventional medicine doesn't recognize or care about my pain, suffering, and well-being.

Yvonne Forey Help us instead of helping yourselves...stop deleting posts and give us some answer... obviously some ones watching to delete..you asked us..answer us!

Jeannie Bonetpels I have gone to 30 doctors in 16 years and in that entire time it was Fibromyalgia and CFS, doctors need more education from you. CHRONIC LYME needs to be taken seriously because those of us that are sick are horribly ill. In 2009, I nearly died from CHRONIC LYME DISEASE. I have lost relationships to this horrible disease. I have been financially ruined by this CHRONIC disease. All we WANT is TREATMENT for our CHRONIC LYME DISEASE and have insurance cover it and to HEAL from CHRONIC LYME DISEASE. By the way, I'm in CALIFORNIA and I'm always hearing, there is no LYME in CALIFORNIA. I'm here to tell you, YES THERE IS. Please give us back our lives, this is criminal not to treat us, we are not LEPERS. Thank you.

Angie Yoho Robertson After suffering for so long from Lyme it still makes me so sad to see how many other people are suffering. I have known it but am praying that the right people finally open their eyes. We have to put a STOP to Lyme!

Cathy Swain Cakebread I would like to see the IDSA revise their guidelines on Lyme Disease so that: patients with Lyme Disease may be properly treated without going bankrupt, so doctors who treat Lyme Disease will no longer be prosecuted for doing their job and so Folks who are bitten by ticks can be properly diagnosed and treated right away so fewer people will suffer the long term effects of this terrible disease!

Michelle Gagnon Please adopt the ILADS guidelines that is based on science, truth and facts that it effects everyone differently. It is hard to test for as it can be in various organs or anywhere in the body. Different testing methods should not be the priority. The FEDERAL GOVERNMENT supports that Lyme Disease should be diagnosed clinically. The first step is to educate the medical community and not frighten doctors for prescribing long-term antibiotics.

If you're scared of the cost issue involved in this, it's probably a lot cheaper to be on 5 years of antibiotics verse 25 years of DOZENS of unnecessary x-rays, ultra-sounds, mri's, heart monitors, hundreds of blood tests that don't show anything. And that's just me. Some people get surgery's and have organs removed only to figure out that it wasn't the problem. It can be psychologically damaging when there is no support from anybody as there is no education and many people look normal. It is complex, therefore get educated by the Lyme Literate Doctors. Sometime you have to suck it up, accept your ignorance and move on to do what is right. The 600 people that have commented here are desperate. PLEASE HELP!!!!!!

Kenneth Damsell stop taking insurance money and start dueing you hipcrital hath or have you forgot that for money for insurance co to dinight lime desease for some one who got it and did not know about being bit by the tick. what about the older people that never new and that years ago.

Michelle Milledge Trostler In 1999 I was bit by a tick in Huntington Beach, CA. 29 years old, totally healthy, not a care in the world and living on the West Coast I had no idea I should maybe go to a doctor. I had the tick in my hand, and put it in the trash. By the end of the day I couldn't hold my head up and had to go home but the next day I felt better. Fast forward to 2011 and I got sick. Really sick. Lyme sick. Sometimes I can't hold my head up just like that day I had a tick in my hand. I can barely work but manage to continue to do so and thank god because the cost of the treatment (which seems to be working me back to health albeit slowly) is CRAZY HIGH. Behind the science that you believe in or do not believe in there are real people suffering. I couldn't make this story up if I tried! Revisit, Reconsider! Lyme is all too real when it is your body that is fighting it.

Anne Killeen I would like to see you stand behind the Hippocratic Oath by recognizing and properly treating patients with chronic Lyme Disease.

Kristie Lohrer I would like to see the Hippocratic Oath taken more seriously.

Diane Janas Think of the money that could be saved if this was recognized and treated correctly instead of diagnosing everything else under the sun and making people try treatment after treatment while they lose years of their lives! Are you afraid of admitting you were wrong? Guess what - you are!! And too many people have and are suffering for it. I wonder what would happen if the president or congress had to live with chronic Lyme disease.

Kimberly Aldrup-Otto The number of these comments are the true Statistics of real human beings that have had there HUMAN RIGHTS taken away from them by non-believing medical providers and greedy pockets. It is a crime in itself.

Darla Brown Please open your mind to the possibility mthat Chronic Lyme and co-infections do cause long term disabilities. Please fund research for accurate testing and a consistent reliable treatment plan for all of us who want our lives back. Thank you.

Ann Maher Please, Please change your guidelines.They follow your guidelines in Europe and I've been ill for 16years. I've had to to get diagnosed privately abroad. BEcause of your ignorance, I doubt I will ever fully recover.CHRONIC LYME DISEASE DOES EXIST!!

Kristie Lohrer Gosh, this is like writing to Santa Clause :O)

Jennifer Fila Like many others here, I'd like to see the ISDA recognize the Lyme epidemic for what it truly is. I was misdiagnosed with MS after SEVEN negative Lyme tests, only to learn later how unreliable the tests are. Several other family members are suffering from Lyme too. We've spent thousands of dollars trying to get proper health care in a society that doesn’t recognize this awful condition. I want to know how the ISDA can continue to deny the existence of this horrible disease?? One prominent Lyme doctor was quoted as saying, "the absence of proof is not the proof of absence". Enough with the politics... people are suffering and dying needlessly!

Christina Ann Change your guidelines and actually help those with chronic Lyme. Stop sweeping it under the rug. IDSA, you are effectively responsible for the pain, suffering and lives of how many? It’s time to help patients, not your pockets.

Jayne Hall Shea It is not about more education, better awareness, thinking outside of the box, studying the research, or hearing our cries for help that will generate true reform in the diagnosis and treatment of this disease. Reform will occur when it is more advantageous to the IDSA to diagnose and treat than to not. It will take a lawsuit of great magnitude to change the IDSA perspective. Only then will there be an" about face" turn in IDSA guidelines. The fear of malpractice will then dictate the appropriate diagnosis and treatment of Tick Borne Illness and Chronic Lyme by the IDSA.

Valerie Mains Wolfer Let's not forget all the children who are being labeled with learning disorders and behavorial problems without first ruling out Lyme. When the parents insist on testing the doctors tell them it can't be Lyme because the test came back negative...the same test the CDC admits is not accurate and should not be relied upon.

Kim DeSantis Goodwin *With the guidelines it seems as though our feelings are correct about the money the idsa makes for keeping this a secret. Of course you know this is a bioweapon made to wipe us out, trick our immune systems and this is not a normal bacterium. You all know that so stop playing dumb. Killing for money is no better than being a mass murderer.*

Kathryn Thorne As stated previously, I, too would greatly appreciate it if IDSA would revise their diagnostic and treatment guidelines for Lyme to include chronic Lyme as a disease and long-term treatment as a viable option, and for treatment to be more readily available and more patient-friendly. This will happen with the help of recognition from the IDSA and with their support against insurance companies refusing treatment coverage and for doctors being allowed the freedom to treat as they see fit.

Did you get that, IDSA? Thanks for asking for our input. We would greatly appreciate a kind ear from you, and for you to give a new focus to Lyme and Chronic Lyme through an unbiased and open-minded interchange with chronic Lyme sufferers and Lyme-literate doctors, and we look forward to working together better in the future. We can't lose sight of the fact that we all share a common goal: to end suffering through diagnosis and treatment of infectious diseases, and we, chronic Lyme patients, would like nothing more than to extend the IDSA's knowledge and treatment base to include this disease which continues to be under-diagnosed and under-treated.

Lynn Baker Lawrence The best testing for Lyme Disease and co-infections, the best research for the best medicines and the production of those medications, the change of regulations so doctors can administer the medications, and a plan that helps people who can no longer work, because of YOUR decisions, funded by the IDSA because the blame largely rests on your shoulders that people are in the condition they are in physically, mentally, emotionally and in the end, financially from a disease that is REAL that YOU choose to IGNORE. Just like the medical community ignored AIDS for 20 years.

Really, IDSA, it is shameful that of YOU that our ID doctors have their hands bound to an ineffective test AND ineffective treatment which cost people their marriages, homes, custody of children, jobs, not to mention they cannot afford any medications after they lose their job, family members who think "it's all in their head", being sent to psychiatrists for no good reason, their ability to walk, talk, see, hear, or have any quality of life, no more daily exercise (is it any wonder there is an obesity epidemic while you are choosing to ignore the Chronic and non-chronic Lyme disease situation in the USA), even the ability to cook because you cannot hold a spoon long enough to stir and have been tested for carpal tunnel and told NO, you don't have that either. Shame on you, IDSA.

And, if you cannot do the above mentioned, or WON'T, how about just being up front with us and telling us WHY you won't. With the evidence before you, and the overwhelming amount of people who are sick in this country alone, how LONG will you choose to ignore this as THE MEDICAL SOCIETY DECIDED TO IGNORE AIDS. Shame on you all.

Dawn Baggett Oversight and discipline of the highly influential teaching doctors who deny accurate Lyme disease diagnosis from knowledgeable and replace with their own unsubstantiated diagnoses. Not only are they putting patients at risk, but they are influencing doctors in training.

Lori Philipp Brunk I am a 7 year sufferer of Lyme Disease. It has infected every part of my body-pain burning, neuro., painful joints. Just found out today my daughter has Lyme. Ugh! Now to find a doctor to stick his/her neck out and treat! PLEASE RECOGNIZE CHRONIC LYME - PEOPLE ARE DYING SLOWLY FROM THIS DISEASE!

Kim DeSantis Goodwin With the guidelines it seems as though our feelings are correct about the money the idsa makes for keeping this a secret. Of course you know this is a bioweapon made to wipe us out, trick our immune systems and this is not a normal bacterium. You all know that so stop playing dumb. Killing for money is no better than being a mass murderer.

Carmela Bonito Recognize chronic Lyme disease, allow for necessary treatment, get the jerks off the board who call chronic Lyme patients "psycho".. they make a fool of the IDSA. Chronic Lyme needs to be properly acknowledged so we can decrease the number of ill and dying patients.

Kim Johnson Siebert Admit it. Chronic Lyme Disease does exsist... and rewrite your guidelines so I don't have to drive 4 hours to find a doctor that can treat it.

Rachel Rajput Stop denying Chronic Lyme's existence and channel these resources into helping those that suffer from it!

Susan R Wetzel I'd like to see the IDSA admit that my entire family of NINE (yes nine!)... along with tens of thousands across America absolutely DO have Lyme Disease and that it's not *All In Our Heads*! I'd like to see testing that completely eliminates the Elisa test and *actually* finds the Lyme disease (and coinfections for that matter!) that is rampant in my blood... but that the Elisa and Western Blot *can't* find! I'd like to see the IDSA step up and *help* all of us who are dieing a slow and horrific death from Lyme Disease!

Faithe Anderson I would like to see my child's Lyme disease treated as seriously and effectively as my dog's Lyme disease was treated. I find it disgusting that my child suffers while the medical profession/insurance companies duke it out.

Joan Metzger please recognize that chronic Lyme disease does exist and help us get treatments....it is very disturbing when drs argue among themselves and are afraid to treat you, but also can't tell you whats wrong other than you having Lyme...you are hurting.

Julie Huneycutt You need to recognize Chronic Lyme Disease. Have appropriate, proven guidelines for treatment. Help people who desperately need help. Educate doctors and the public. Why has this been such an issue? Do something! Every day you hold responsibility for your non-actions. What are the results? Deteriorating, struggling individuals and families. Wake up, own up, and change it up in 2012!!

Julia Maria Pilliod-Egan Start by having an emergency board meeting and look at each other in the face and figure out how you have failed. Then start firing a bunch of people and bring in some fresh talent. Chronic Lyme Disease will be written in the history book as your greatest human failure. I had 15 years to live like a dead person with untreated Lyme. 4 years yes, F O U R, in addition FOR TREATMENT... NOT TWO WEEKS !!!! Spending my families life time savings to try to save myself. Most was spent on IVs and Ports, medications, and other treatments to the tune of sever 10's of thousands of Dollars. There are thousands and thousands of us. 2012 a new year for you not to HATE US AS MUCH AS YOU DO. And we are not terrorists for asking for basic human RIGHTS !!!!!!!

Heirloom Hourglass Change your Lyme Disease Guidelines to the ILADS guidelines which are actually tried and true by real doctors that care about helping their patients with this HORRIBLE disease and the co-infections associated with it, not just lining their pockets with money for denying the severity of it & correct treatment. It will all come back to "BITE" you, most likely literally, someday unless you get on board and really start trying to find new ways to prevent, diagnose, and CORRECTLY treat this worldwide epidemic! The number of sufferers is growing & you won't be able to ignore it forever. Why don't you just do the right thing?

Sonja Fischer Überarbeitet bitte dringend eure Leitlinie zur Behandlung der Lyme-Borreliose! Sie ist auch in Europa Grundlage vieler dort verfassten Leitlinien. Aufgrund dieser Leitlinie bin ich 14 Jahre lang fehldiagnostiziert und fehlbehandelt worden. Heute bin ich schwer und chronisch krank.

Kristen Smith Recognize Chronic Lyme disease and revise your guidelines so that those who suffer from it can be treated, and so that doctors can help these patients. Your leadership, vision and compassion are needed.

Hootan Veeh Study Lyme Disease and especially Bartonella Species in humans. Help other doc's besides ID to be able to identify tick borne diseases earlier and more accurately.

Marie Rosenberg Kovitch My son got sick a couple months after graduation and the last 3.5 years have been spent getting false or incomplete diagnoses. Countless ER and doctor visits later, Igenex finally confirmed Lyme. None of the many doctors/specialists ever brought up Lyme to us. Finally, I found a wonderful doctor who is helping my son's body start to heal from what Lyme has done through these years. He already feels improved energy but we have a long way to go. Lyme has sorely affected my son's body, mind, spirit, goals, relationships, faith, sense of security - every day. The delays in a full diagnosis and treatment, the exhausing obstacles, the hefty financial bills, and most importantly, the years full of frightful and confusing days and nights my son (and his father and I) has had to endure have all been due to the fact that Chronic Lyme is not recognized properly, and IDSA is important part of this huge difficulty.

Snap Crackle Pop Amen, Michelle Gagnon

Valarie Murphy Now if I go to a doctor who treats me with contempt, I walk out and refuse to pay. I tell them why.

Deborah Via Dixon Yes The Hippocratic Oath . . . good point,,in it's definition is "to do no harm" doesn't look like you follow that golden rule. WAKE UP! Your useless, nonsensical guidelines ARE hurting people every day. What if it was YOU, or your CHILD, or someone you LOVE or someone you know. The longer the blinders are on, the closer YOU are to one, if not more of those. It's only a matter of time. We NEED and WANT acceptance, treatment and research N.O.W.

Agnieszka Gro A little awareness of chronic Lyme disease in my country and more ILADS doctors.

Amy MacWhirter Please study the Lyme bacteria....and how it works...then you will see how it is so different than others and how often it goes chronic due to the way it evades the immune system so amazingly! Please do this to save our country! Also please study the chronic Lyme population to see that this IS being sexually transmitted!! AND from mom to baby! Plus the fact that an infected person sends out phermones for a new bite...and these new bites more often than not contain MANY tick-borne co-infections in these bites. I was rebit and it debilitated me. I saw 40 docs (who were following the IDSA Elisa testing) and they each dismissed me not knowing how to treat me. I ended up having ALS and MS symptoms and only then I found a doc who treated me clinically and having chronic Lyme/babesiosis/bartonella and many other infections. Its taken me 5YEARS of treatment and I'm finally now starting to be able to drive and have some type of normalcy in my life... These guidelines would have KILLED ME! In fact it kills many people every year. Thing about this and LISTEN to us patients!!! Thank you...

Dana Rivera Lyme Disease is at epidemic proportions. People are suffering and DYING. Lyme is the worst disease anyone can experience. Will it take one of the IDSA doctor's or family members experiencing Lyme for years for things to change? Chronic Lyme exists and you know this, yet nothing is being done. You know the Lyme bacteria is more virulent than Treponema pallidum. Yet nothing is being done to help those suffering! When will you help? Stop pretending and start acknowleding those that are sick and dying from Lyme and co-infections! Change the guidelines!!

Carol Snow Milne Previously healthy and active adults with so much to live for find themselves totally disabled. Recognize the affects of chronic Lyme disease or complications because of the disease. Thank you!

June Whitehead i suffer everyday from Lyme disease!the guidelines need to be changed why are we constantly refused help!!!

Victoria Ava I will add my post/voice.... please please revise your guidelines and start taking Chronic Lyme Disease and Chronic Tick Co-infections seriously instead of just saying it is autoimmune and only palliative measures can be given. People stay months and months on abx for acne, but yet the IDSA is against long-term antibiotics for Chronic Lyme. Truly- what is worse, Chronic Lyme or Acne?

Susan Ash Access to treatment covered by insurance that will truly restore us to the best health our bodies are capable, the respect we all deserve that other chronically ill patients receive. I was a FORESTER and went to 10 doctors who all told me to seek psychiatric health until a pain clinic of last resort finally tested me. Positive of course! If I am ever told by another infectious disease doctor that all I need is to "take my life back, stop your meds, and get exercise..." Wait, I'll never hear that again because I will never put myself through the torture and abuse of seeing another infectious disease doctor again. And I'm still sick. 5 years and I'm still sick.

Nancy Mitchell Lyme 7 years this April. Turned away by an infectious disease doctor (I use the term doctor lightly). I would like to see treatment for all. I want doctors to take me and others with Lyme and company seriously. If you can not do this, step down.

Stacey Lynne Dalpe Change treatment guidelines, Improve tests, Make western blots part of your yearly physical, Health insurance to actually cover treatment after 30 days, Admit Lyme can attack all parts of the body, Admit there is chronic Lyme, FUND RESEARCH! I could go on and on....

I was sick for 2 years before diagnosed. Diagnosed with 13 bands reactive on my WB 11/29/10. By 4/25/11, 5 months later my heart was failing and I had to go in for open heart surgery to replace my aortic valve and rebuild my aorta. I was on the picc line for only 5 weeks when we found out about my heart. They had to stop treatment immediately. Not to mention the 2 months of doxy I did. I have had so many things happen to me over the past 3 years it is not even normal. I am unable to be treated by a picc line now... (because of my heart) Still symptomatic of course. I also have 2 co infections. I have only known I have Lyme for a little over a year and in this past year my life was almost taken from me..... LYME SUCKS!

Julianne Zhou One word. Listen.

Mich Elada Focus on Protomyxzoa rheumatica as a possible cause for many chronic autoimmune disorders.

Nicole Conti Harris Please change your guidelines for Lyme Disease. There is such thing as chronic Lyme and I have suffered with it since I was 10 years old (now 25) Misdiagnosed for 4 years with Mono, vitiligo (as it has affected my skin) and tested for Lupus etc which none of them I had. Please prevent further suffering by funding and educating our medical field about Lyme. Please help to answer millions of questions to those who are suffering with this disease.

Jim Price How about a real nationwide truth campaign, for a change.

Jacqi Euler This is a video from Dr. Yost, you should watch it, very informative! http://www.youtube.com/watch?v=EwW0-ky7DdY&feature=plcp&context=C3555110UDOEgsToPDskIbSL_rIun5P-AK2feOCtb-

Snap Crackle Pop An excellent video to watch:http://www.youtube.com/watch?feature=player_embedded&v=EwW0-ky7DdY A Medical Doctor who contracted Lyme, witnessing about it.

Ellen McDowell Ruggles I'd love to see more done for people who now suffer from Lyme disease or will in the years ahead. A diagnosis was a long time in coming for me, and now my primary's preferred medication to treat me is no longer available at my pharmacy. I know more people who have experienced the effects of Lyme disease than any other infections or diseases added up. Why is that, I wonder? Greater understanding is gaining ground, now let's get going with better diagnosing and treatment.

Lori Hoerl It would make a profound and groundbreaking mark on the medical community if the IDSA would acknowledge the existence of chronic Lyme disease, the severity and devastating potential of under-treated and untreated Lyme, and the need for open-ended treatment based on each individual's clinical picture and the clinical expertise of the treating Lyme physician who knows the most about the patient and the most about disease. It would shatter the obstacles to treatment we now face if the IDSA officially stated that chronic Lyme disease exists, changed its guidelines to endorse open-ended treatment similar to the ILADS protocol and acknowledged no one has all the answers but that some have significantly effective options that all infectious disease physicians should know like the back of their hand. Because Lyme is EPIDEMIC and deserves the validation, research funding and aggressive efforts to treat it and beat it equal to those we now see for AIDS. In the end, sicker patients untreated can and have died. The public needs to hear that truth from you.

Laurie Bentley Christeson Revise the Lyme disease treatments guidelines - need more research on chronic Lyme & long term therapy & new reliable testing. Need more education for doctors to be able to diagnose & treat.

Bonnie Gilbert Please stop letting money, politics, popularity and embarrassment do harm to the people you have sworn to help. Readdress the Lyme Disease guidelines so that doctors have the proper tools to effectively treat each individual patient based on their symptoms and medical needs. Expand education programs so that all doctors from all fields can recognize Lyme Disease and their patients can get proper treatment.

Jim Price How about no more secrets, tell the truth!

Michelle DeCiantis Collette Please begin to accept Chronic Lyme as a REAL disease!!! My kids just lost their pediatrician because she isn't willing to go against your guidelines for treatment! Now I don't know what to do!! I'm not willing to give up their treatment but WHO will their PCP be??? Help me!!

Jan Chimchirian For Lyme Disease and co-infections to be taken seriously, not become a cash-cow for the medical industry and quack rheumatologists, neurologists and other specialists who search only for what they want to treat; usually CFS or Fibromyalgia. I have dealt with incredibly arrogant and incompetent specialists for too many years now, when a simple course of antibiotics would have cured me over a decade ago.

Virginia Wuellner Ward PLEASE recognize the existence of chronic Lyme disease! I have had it for 10 years, with a verified tick bite, positive IgM test and low CD-57 levels, plus clinical symptoms of Lyme. Please revise your guidelines to allow for longer antibiotic treatment for chronic Lyme.

Jennifer Roswell IDSA---its time you either shut your doors or do the right thing. The fact that you will not recognize the epidemic of borrelia burgdorferi (Lyme) in this nation is shameful and embarassing. Its not even science. Its the flat-earth syndrome. You undermine your credibility in all areas when you allow this to occur.

Steve Mayernick Take Chronic Lyme seriously. It isn't in my head. I'm a 24 year old former collegiate athlete, I don't have MS, fibromyalgia, AND chronic fatigue syndrome. Get. Real.

Valarie Murphy If just one IDSA guideline writer contracted late-stage Lyme, everything would change. Volunteer as research subjects, fellas.

Kathy Obal Carlstrom A strong public awareness campaign regarding the transmission routes of Lyme disease and the various co-infections (strains of mycoplasma, babesia, bartenella, HHV-6, and many others) is desperately needed. These infectious diseases are in my opinion both sexually & mosquito transmitted. Transmission is not limited to certain types of ticks. Let's assume they may be transmittable by other biting insects as well. Transmission does not take 36 hours but just a matter of seconds. The degree of misinformation to the public is dangerous to public health here and internationally since your group has a broad scope of influence. People have a right to know the basic routes of transmission. More research in this arena is needed ASAP.

Valarie Murphy Have you all seen the IBM Watson commercial. Computer assisted diagnosis: Lyme. I'm betting someone at IBM in New York has Lyme. http://www.youtube.com/watch?v=RWK-v6e761M&feature=results_video&playnext=1&list=PLFAF617C5820A71FB

Jasmyn Campbell when it comes to Lyme disease and co-infections .. quit hurting, start helping

Julie Searcy Anderson I would have thought ignoring AIDS for 20 years would have been a lesson learned....

Mike Hitch IDSA - man-up, chronic Lyme is the real deal and thank God that there are doctors out there that realize this OBVIOUS FACT! They need to be able to practice their REAL medicine for this REAL condition. IDSA needs to come into the 21st century and recognize Lyme and tick-borne illnesses for what they really are. Is it the bureacracy that causes you to be behind the times? Is it ignornace? Is it political (insurance companies, drug corporations), what is it that such an obvious and terrible condition can be denied by a supposedly reputable and, one would hope, cutting-edge organization like IDSA? It's time to stop with the denial and get moving with some real and plausible ACTION.

Amy Jo Sirianni Allow doctors to treat chronoc Lyme with longterm antibiotics. Push for legislation to protect doctors. Check the success of doctors who have treated chronic Lyme. Believe the research that shows spirochetes entering cells, and residing there for long periods of time. Check the research that shows the three forms of the bacteria. Understand that many multi-sytem diseases, including those which deplete your immune system, need long term care. TB, and Aids to name two. Lyme is just as serious, and can be deadly. Don't wait any longer in providing bacteria ridden people the best chance regaining a productive life.

Isaiah Goodwin I have suffered with Lyme disease for almost a decade, maybe more. I lost the quality of my life and i did give it to my pregnant wife and then she gave it to our unborn daughter. We suffer everyday in so many ways that i could not write it all in one day. It is like hell if there is one. You wake up and think how am i going to get through another day. How is my wife going to feel today and what is my daughters future.

I have 24/7 tingling in my arms, legs, hands, electrical feeling in my head, random rashes, arthritis pain, joint pain, knees ruined, soles of my feet hurt to walk on, i live in the bathroom, my anxiety is out of control, depressed never thought i could be i was always happy, i was a semi pro boxer and soccer player perfect shape and health. I get allergic type rections everyday, im moody and angry now, shoulder cant lean on it, sleep on it, insomnia all night tired all day, i slur my words like im stupid, no train of thought, cant spell anymore, drop things, forget everything, no circulation in my calf muscles or hands and there is so much more. Tested negative for the fake elisa test but the western blot over the phone tested negative cdc didnt know enough about it so i trusted the test, 4 years of going to the best specialists in the world not'one dr could help me. One year i had to libe with being told i had ms, 2 years i had fibro and diagnosis taken back to we dont know go on tjis depression drug and get some joint shots and let me make you brain dewd on lyrica and gabapenten and gain 30 pounds.

Susi Kaster Glaeser *Please recognize that Chronic Lymes does exist. I have had to stop treatment since the only doctors who treat us properly do not accept insurance. I believe YOU owe me thousands of dollars due to your ignorance. Let this open your eyes...*

My wife all different symptoms than me same co infections, same illness the onoy thing that is the same ie we feel liie we have the flu everyday. If when i walked into that drs office with a red rash and a tick bite but tested negative for elisa test had i just been treated i woudnt have ruined 3 lives or my dr or i shouod say the IDSA you robbed me of a decade of my life, my beautiful wife cries everyday in pain and my beautiful precious daughter lives with this nightmare. This is not'some discomfort this is hell. Pain meds dont touch it, sleep cant it hurts to much and it never gets easier every day is a battle. Please dont kill us slowly anymore. What happened to trusting drs to heal. Change is needed so much of it

Randy Garvin WHAT WOULD WE ALL LIKE TO SEE?
1. The IDSA to review every-single one of these posts, listen & change the way you recognize Lyme + co-infections.
2. To get the doctors in the US trained by a Lyme-Literate Physician so the following stories on the attached site + the people who are not on this site will no longer happen! http://www.Lymememorial.org/

Kristine Marcello Hall Like most people here...I've been affected by Chronic Lyme for some time, I'm CDC positive and have been treated but if I were treated according the ISDA recommendations and didn't live in a state that enacted legislation to protect those with Chronic Lyme, I don't know where I would be! Please ISDA review your guidelines, there's an entire population suffering because you won't admit you were wrong.

Susi Kaster Glaeser Please recognize that Chronic Lymes does exist. I have had to stop treatment since the only doctors who treat us properly do not accept insurance. I believe YOU owe me thousands of dollars due to your ignorance. Let this open your eyes...

Karen Hart Acknowledge that a mistake was made - "New, overwhelming evidence has come to light" or some such lead in would be good to start with. We, those suffering with this disease, don't just sit around looking for something to harrass you about. My husband was tested for Lyme only after all medical had failed and we were preparing for him to die. The Internal Medicine dr. that ordered the test even allowed him to be tested while he was on an antibiotic for a sinus infection. Of course the results were negative. Another dr. tested him 14 days after the antibiotic stopped, and he was positive by CK.

Lyme Digest It is time to update the Lyme Disease Guidelines! Chronic Lyme disease exists. It is amazing to read all these posts. Please consider the patients when you improve your guidelines.

Neil Huey The ISDA should choose to err on the side of caution in terms of their stance on chronic Lyme and "associated" tick-borne disease. It is perfectly acceptable to change your mind/opinion with regard to the body of scientific evidence as more clinically sound information on tick-borne disease becomes available. Additionally, insurance companies should err on the side of caution. Antibiotic resistance is a valid concern, due partly to the overuse of antibiotics, as well as patient safety issues in prolonged antibiotic therapy. Guidelines and power wielded by such entities should not dictate protocol nor lead to the point of medical license revocation from those who have demonstrable knowledge and dedicated their careers to those treating tick-borne disease. Nor have the patients lost their "own rights" to partake in the benefit/risk decision making process?

Patients should be allowed to be treated individually upon their: history/physical/presentation/manifestation/cascade of health events, etc... for they may have been disease ridden for years. Many things play into the perpetuation of confusion in LYME i.e., Semantics: Lyme vs "tick-borne disease" CDC revision/distinction of acceptable diagnostic tests...misguided, lack of distinction between the "accepted" tests...diagnostic tests for the clinical evaluation of a patient should have much better sensitivity/specificity. Why has this not been changed by the CDC???

Similar to sphylis (which has been taken seriously in terms of deliterious, long-term health consequences) in terms of it also being a spirochette, Lyme very frequently is not the only pathogen delivered during a tick bite - babesia microti, bartonella... The U.S. Center for Disease Control and Prevention is alarmed about the rapid increase in infection rates

Karen Hart CDC standards. Treatment by an LLMD has enabled him to get back his life, though the rest of our family has now come down with the disease. We want education for the drs., we want education for the public, we want our lives and health back. Before you wind up in the same boat we are in, join us in fighting this disease and not just being a stumbling block on our road to health!!

Valarie Murphy One of these days, there will be a class action lawsuit.

Niki Mitchell would like to see the IDSA take Lyme Disease more seriously, and revise the guidelines regarding it. I have spent more than 5 of my 19 years of life with Lyme Disease...and only one year actually knowing what was wrong with me. I never saw a tick, a bulls-eye rash, or had flu-like symptoms. I had a negative ELISA and western blot. If only any of the 25+ doctors and specialists I visited (before finding my current doctor) had been accurately educated about Lyme, maybe it wouldn't have progressed to be the chronic, debilitating illness it is today. But I am slowly but surely on my way to recovery...and I have my doctor who works outside of the current IDSA guidelines to thank for that. The saddest part is that my story is not alone. It's almost identical to that of not only my little sister, but an absurd number of people. Please do something to stop that number from getting higher.

Beth Schultz Wow, I think you got your answer. LYME DISEASE!!!!!!!!!!!! Please help us I have been sick for 7 years. I tested CDC positive from the begging I now have 9 CDC positive tests still not one ID DR in my State will treat me. DO you see a problem here. I sure do.

Mike Hitch here's the way to contact IDSA the old-fashioned way:http://www.idsociety.org/Contact_Us.aspx

Jessica Rain Real

Donna LeBlanc soo many people including my self have been left undiagnosed for years ,,,,Me 10 plus... so now my body have been invaded!! simply heart wrenching to know all the suffering could have been avoided.. If Our Dr.'s wer educated better. And standareds for testing were better. AND Dr.s could treat with out being harrassed... It's a shame people have died form this disease.... and so many more are left untreated... Is this really the USA... I can't beging to tell you how much money I have wasted on varouse treatments that were all a farse... to try to gain my life back... I have lost the me I used to know.. I do not know what a day is like with out some sort of pain, discomfort. I can't sleep well.. It's just a big mess... YOU ALL Should be ashamed of your selves... Makes me sick to think about it... GET OUR PEOPLE HEALTHY AGAIN!!!!

Michael Welch I would like to see you guys finally accept that Lyme disease is a real illness. I have three friends with this debilitating disease, and it is horrific.

Lori Baker Hansroth IDSA, please, admit that you don't have all the answers and that you really don't know all the questions. Open your eyes and ears and listen to the patients and their families who are on the frontline fighting a disease that doctors and insurance companies say doesn't exist because your guidelines allow it happen...families who have lost everything and still keep fighting and educating others so that it doesn't happen to them. IDSA, it's time to get honest and real about Lyme disease and to give it the attention it desperately needs before it kills even more people.

Dedee Simms Millage Why, I give you kudos for asking... Add one more request to acknowlege and treat CHRONIC LYME DISEASE. All frustration aside, if you really care about what the PUBLIC would like to see from you, we REALLY need some help. Better testing and treatment. If you care about the human population this is the perfect chance to make a change. We don't care that you've been wrong all this time, start now, make a difference NOW. In the end, we'll love you for it! Symptoms increasing for 10 years. Tick bite - THIRTY YEARS AGO! In my hair, so no visible rash (if there even was one). THANK YOU

Mike Hitch The irony of it all - the IDSA has something go VIRAL on them! LOL.

Shannon Tracey Take on chronic Lyme disease, which has dramatically impaired my father's health for nearly 20 years.

Kendra Stone Revise your guidelines and start taking Chronic Lyme Disease and Chronic Tick Co-infections seriously! Chronic Lyme disease DOES exist. Stop letting money and politics, do harm to the people you have sworn to help. People are suffering because of the lack of adequate diagnosis and treatment. Champion better testing and access to treatment.

Jean Hemond It is outright criminal to maintain your flawed guides lines about Lyme Disease. This while a number of your voting members are in clear conflict of interest in bed with denial benefiting medical industry interest.

Pam Thomson Please recognize and acknowledge that Chronic Lyme Disease does exist - not only in the USA. It is worldwide now - even in South Africa despite that our Gov Health Department denies this fact! Please listen to those who have suffered year after year after year with no relief. It is a living death and no one deserves to suffer the way Lyme patients do. The doctors who have got it right are harassed and prevent from treating their patients who are actually doing well on their protocols. Please re-address your Guidelines so that millions of people can get treatments that work. Treatments that address the root of the problem and not just mask the many symptoms. Thank you.

Denise Jaffe How about Lyme education for ALL doctors, since Lyme (and co-infections) exist EVERYWHERE! I was bitten by a tick in Southern California, removed the tick the wrong way, had a bulls eye rash that expanded around my ankle and up my leg, had a positive spinal tap for meningitis,was flu-like for MONTHS,and then suffered with neurological problems for 11 years before I met a Lyme lit M.D., and he tested me for Lyme. The test came back positive.For years I was called crazy, I was sent for psychological help, and I spent THOUSANDS of dollars on co-pays,while insurance paid millions of dollars on tests, scans, and UNNECESSARY exploratory surgical procedures.

I was never on disability-because without a name for what I had, "obviously", there was nothing wrong with me. One minute I'm fabulous, one minute I'm out cold-try holding a job like that! IDSA. PLEASE HEAR US.

On year #11, I finally got the I.V. antibiotics I needed through a picc line. I now had 4 Board Certified Lyme Literate M.D.'s who concurred I needed at least six months of the abx (Rocephin). Insurance cut me off after 30 days,even though I was doing beautifully. Insurance covered the picc line supplies and the HOME VISITS FROM THE NURSE FOR SIX MORE MONTHS-BUT NOT THE ANTIBIOTICS THAT GO IN THE PICC LINE. I relapsed the week I was taken off the abx. PLEASE HEAR US.
Yes, I'm told I "don't look sick". I also don't take and post pics the days I am unable to walk across the room...or the days my blood pressure drops so low I am on the floor until somebody finds me and physically picks me up.I don't take pics when I am in my neck brace because I can't hold the weight of my head.I don't post pics from the Cardiologists office while I am being checked for my scary strange heartbeat.I don't post pics when my eyes droop from weakness. I don't take or

post pics while I am at UCLA and Cedar's Sinai getting my liver lesions checked out-those pesky lesions bulging out of my ribs causing pain-those lesions that were not there before the tick bite, but now there are more than 20, up to 8 cm. Now there is one on my spine. I don't post pics when the rash flares up. I don't take or post pics when I am lethargic from fevers-shall I go on???

P.S. I also appealed the decision from insurance THREE TIMES. Try doing that while you are weak with the picc line still in your arm HOPING for the decision to be overturned. Thank you for listening.

Trisha Ann Kelton Collins My child suffers everyday and IT IS LYME DISEASE. Just listen & make changes on the way you recognize Lyme disease and co-infections.

Jessica Rain Realize that your system is corrupt with conflicts of Interest and anti-science. We the people have suffered at the hands of your outdated guidelines for far too long. Take your greedy hands out of the insurance companies pockets and care for patients without hesitation. Realize that other countries adopt your guidelines without question. The spread of misinformation and fear you have created is far reaching and harmful.

Danny Troye-Rivera Acknowledge and educate doctors on treating the very real threat that is chronic Lyme Disease. The disease is the most horrific thing I've witnessed and endured myself. The suffering cannot be described in words, and the number of victims is astronomical. It is absolutely absurd to ignore such an incredible threat to the vitality and health of human beings and it needs to be addressed and fought against accordingly. HIV gets the recognition it deserves, MS does, Lupus does, cancer does, but Lyme Disease simply gets swept under the rug despite being a life threatening, lift-altering, and absolutely traumatic disease. This is unacceptable.

Liz Karkoff I would like to think of the IDSA as "my society" but that would be impossible. When I first became sick in the summer of 2006 I went to see the doctor who is probably _the_ most prominent IDSA Lyme "specialist." I presented with obvious symptoms of Lyme and ehrlichiosis and he told me that I had a virus since my blood tests were negative. When my symptoms didn't resolve after a few months I was told that I should go see a psychiatrist to get help with my psychosomatic issues. I feel so lucky to have found a knowledgeable LLMD who is bringing back my health. I wish the same for every person out there suffering from chronic tick-borne lillnesses. Some day the truth will come out and patients will get the proper care for tick-borne illnesses. I can't understand how someone who has taken an oath to protect people's health is actually doing the polar opposite. It's a disgrace.

Dedee Simms Millage BTW, I'm in Colorado (from California), and everybody knows, we don't have LYME in Colorado. WE DO. And let us know if you decide to re evaluate this subject. A lot of us would feel SOME sort of peace knowing you are listening.

Lynne Novak Harmelin You all at the IDSA know what needs to be done. Now do the right thing.

Clair Smith I would like to see the IDSA have honesty regarding chronic Lyme disease. Your suppression of the true facts of this disease which is growing exponentially and much faster than AIDS has caused immeasurable suffering and pain for hundreds of thousands who are not being treated properly. Ever hear of co-infections? They can't be successfully treated in 3 weeks either. You can't ignore the facts. They are stubborn things just like those rotten spriochetes. Your omission of facts and commission of lies goes against your hypocratic oath. First, do no harm. Have mercy, IDSA.

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Nancy Baumgartner Please listen to those who after years-even decades- of misdiagnosis and/or inadequate treatment for Borreliosis (and co-infections) when they report what finally brought answers and relief from their physical and psychological misery. Please review and modify Lyme diagnosis and treatment guidelines so that people can freely get effective treatment and docs who heal have nothing to fear.

Libby Foster First, I would like the IDSA to listen to the people who have Lyme. Second, I would like to see more awareness about Lyme disease- it affects and infects more people every year than any other chronic infectious disease. Chronic Lyme is real. I know it's real and my mother for over 40 years definitely knows it's real. (From Wisconsin)

Neil Huey Your (ISDA) argument of chronic tick-borne disease "not existing" does not hold up scientifically. As Niki stated in her comment moments ago...she never saw a tick, had a bulls-eye rash, or flu-like symptoms. So for arguments sake, let's assume she did get bit by a tick which delivered virulent borellia and possibly other virulent pathogen(s). Several years go by and she presents with a multitude of health issues. Has that type of patient been incorporated into any double-blinded, place-controlled, randomized clinical trials?

I trust the answer to that is probably not and the argument may be...that it would not be ethical to purposefully infect someone with a virulent pathogen(s) one of which is a cousin to sphylis! How can you then say that chronic tick-borne disease does not exist? How are you as an ID physician (or any physician) even going to begin to make a differential diagnosis let alone one based on sound diagnostic test results? And if you do get a positive Western Blot, what other tests will you run to rule-in/out other tick-borne disease? And...can those pathogens be easily cultured so that you can determine what antibiotic to use? Are you beginning to realize that people other than physicians treating chronic tick-borne disease can have clinically sound opinions which have scientific merit and can differ from your own?

John Wilguess Thank you for asking. I would like to see a unified effort to understand and treat Lyme Disease and the co-infections. In Oklahoma, we were told directly by specialists in your field that Lyme did not exist in Oklahoma, therefore there was no need to test for it and certainly no need to treat my then 15 year old daughter. Yet I talked to veterinarians and tick specialists at Oklahoma State University who study Lyme disease in wildlife and pets in Oklahoma. So the standard for understanding its spread and its transmission, within your specialty, seems to be trailing that of other disciplines which treat animals for it constantly - in a place we are told it doesn't exist. Both circumstances can't be true - isn't the aim of science to resolve these kind of questions? Do Lyme infected ticks exist in Oklahoma and therefore have the capacity to spread the disease here or are veterinarians mistreating thousands of animals in Oklahoma every year? Our daughter, and thousands of others, are just asking for a realistic response to their very real infections. Please help!

Dana Rivera Just saw the IDSA quote. Recent articles from some of the IDSA’s top Lyme guys call Lyme patient advocates a “threat to public health.” Why are we a threat? Is it because we know and have experiencedd something so horrific you have to keep the general population in the dark? Let Lyme "out of the closet" arlready!

Michael Parent Thanks again for giving us all this opportunity to voice our interests in the IDSA's upcoming year. I'd like to add one more issue of great interest. I would like to see physicians better educated on tick born infections in general. It is all too common to go to a physicians office with a clear tick bite, and to hear "Ok, I'll order an ELISA in a few weeks and let's start you on an antibiotic for Lyme Disease." The controversy as a whole has nothing to do with what I'm requesting, as I'm sure your society and many physicians reading this can attest to. Our focus on Lyme Disease has completely overshadowed considerations for infections that are on the rise, such as Babesia, Rocky Mountain Spotted Fever, and other well established infectious diseases that don't "always" require an antibiotic that targets bacterium alone, but may also require antiparasitic therapies.

I am well aware that your society has been undertaking research on some of these issues, but physicians need to be clear that if they see a tick bite, or Lyme Disease, or anything remotely resembling any type of infectious disease that is common to ticks, then they need to consider the broader issues at hand rather than focus on only one thing, like Lyme. Your research lately has come to the same conclusion, so please advocate on behalf of patients and physicians that where there is a tick bite (or suspected bite), physicians should think "Tick born infection, not just Lyme."

Albert Whitehead i watch my wife suffer horribly every day all because of your flawed guidelines and poor testing for Lyme disease this is crimminal!

Becca Epstein I would like to see more respect for Lyme patients as real people, who suffer and feel like everyone else. Almost none of us are making it up, or stupid enough to be hoodwinked by charlatans, or whatever you guys think goes on. We are actually sick, and we wish you cared. This isnt about money or policy. It's about people. And lives.

Anni Garrett Don't allow Health Insurance to deny Lyme applicants to be insured! Make them pay for their treatments.

Neil Huey Didn't the CDC just sponsor a new law being passed December 17, 2011, because of Lyme now becoming epidemic? Something tells me this acute and possibly chronic infection will now be receiving the attention due in the upcoming months.

Michelle Kopp CHANGE!!! If a member of the board could just be me for one day that would be all it would take. Please don't ignore us anymore. We are real people: kind, loving and yes, fighters. Please open your hearts to us.

Valarie Murphy Medical College of Wisconsin just got an NIH grant to study Lyme protein. In spite of IDSA, we're having a little progress.

Nicole Mayo same as these people.

Beth Pearl Schwartz Your current guidelines have made the past two and a half years a nightmare for me. I am not exaggerating when I say that I have even considered ending my life due to the horrible pain and symptoms. There is nothing worse than being told you need to see a psychiatrist by doctors you have trusted and seen for years...just because they don't understand (or aren't allowed to treat) chronic Lyme.

It's not fair that I tested CDC positive for Lyme, but cannot get treated in my own state! And add to that the fact I have to pay for my appointments and treatment out of pocket--it's not right at all!!!

Please do the right thing and revise your guidelines. Educate yourselves and the medical community. Please listen to us!

Faith Strickler I would like to see a recognition of the seriousness of Lyme disease among the medical community.

I was bit by a tick and three weeks later became sick with flu-like symptoms. My symptoms never cleared up and after just two weeks I had obvious neurological involvement.

My Western Blot came back negative but I KNEW I was sick and I KNEW from days and days of research that I had Lyme disease.

Standard medical practice says that just a few weeks of antibiotics will clear up Lyme disease with no problem. Well, here's the problem: after 8 weeks of antibiotic treatment I started to see improvement. Had I stopped after three weeks I would have continued to get very ill.

It has been 8 months now and I am still not better. I am GETTING better, but I am not 100% yet.

Valarie Murphy @John Wilguess, a very thoughtful post. I got Lyme on the NE Oklahoma/Arkansas border. Three other members of my husband's family got it too.

Stephanie Neidig Chronic Lyme disease exists. People are suffering on a daily basis because doctors do not understand the disease and insurance companies are shutting down doctors that do understand the disease and treat it accordingly.

Darlene McMahon Work TOGETHER with Lyme specialists and ILADS. Drop the egos.

Amanda Bern Thank you for asking. A finding, written in clear language, in a prominent section of the Lyme guidelines, which acknowledges the presence of research indicating that the science of the disease is conflicting at best, that the IDSA panel could not even agree the testing is reliable, that there are two standards of care (ILADS and IDSA) and therefore treatment of the disease should be left to physician discretion. Also, a press release stating the aforementioned would be helpful.

Sarah Jean I want the IDSA to aggressively research and treat tick borne infections the same as AIDS or Syphilis.

To believe that tick borne illness can't exist in all states/countries/territories is beyond ridiculous. People travel. Animals travel. We are not idle and stationary beings.

Do ticks see a state border/street/whatever and stop to think, "Oh, I can't possibly cross the street, because I won't be able to exist over there..."
Ridiculous.

Joan E. Nielsen In Denmark our politicans say we follow IDSA guidelines, and Lyme with co-infektions is a very big problem here in Europe too, many is misdiagnosed because of using the ELISA test as the only test, a negative test no treatment, and if the test is positive we must be lucky if we can get 10 days of antibiotic, most docs don't even know what to say or do for us.

Now we pay for better testing and treatment in special centers in Germany, the tests shows chronic infektions and the longterm treatment is hard, but it works very good for most of us. I don't know what we should have done without those German Lyme docs, but not many danes can afford this and we can't too, houses money gone and the bank want fees from our loan..

Please listen to all those patients in your own country and us in Denmark and every other European country too, we are very depended on your decision about your guidelines. Belive this is real, but an early better treatment can prevent years of problems to your helthcaresystem and reduce suffering and expensive medicin for the Lyme patients!

Katerina Baboulas Lyme-Cfids Lyme patients are DYING. Please consider the ILADS doctors guidelines and treatments as they are having success with their patients. 1 month of anti-microbials after yrs of illness if a slap in the face to those ridden with disease.

Erik Skitch Matson changing the guidelines for Lyme disease so it can be diagnosed and treated in a more adequate manner.

Alison T-baum I would like to see the IDSA take Lyme Disease more seriously, and revise the guidelines regarding it. I have spent more than 10 of my 23 years of life with Lyme Disease...and only one year actually knowing what was wrong with me. I never saw a tick, a bulls-eye rash, but I had many other classic symptoms. I had a 2 "false positive" ELISA, 1 "false positive" western blot IgM and one "false positive" IgG before I was diagnosed. If only any of the doctors and specialists I visited (before finding my current doctor) had been accurately educated about Lyme, maybe it wouldn't have progressed to be the chronic, debilitating illness it is today and I wouldn't have needed a PICC line and 6 weeks of IV Rocephin. But I am slowly but surely on my way to recovery...and I have my LLMD to thank for that.

The saddest part is that I am not the only one who has had to go through this. My story is almost identical to that of an absurd number of people. Please do something to stop that number from getting higher. Please allow me to get the treatment I need to live the life I want! DROP YOUR EGO ABOUT LYME DISEASE AND LET THE PEOPLE WHO NEED HELP GET IT WITHOUT FEAR!!!

Elizabeth Henriksen Carrier My life has been totally altered from it's original path because of Lyme disease and it's co-infections....I am no longer that person ...I would like to be acknowledged and not swept away any longer...chronic Lyme does exist...the guide lines need to be revised.....I would like all Dr's to have the real facts about this epidemic and their rights to treat their patients as they see fit...for these things to happen I feel that ego's need to be checked at the door & make it illegal for anyone to profit in any way shape or form who is part of revising the guide lines....I would like them to wake up and hear us who are sick & suffering and for the millions to come if they continue to ignore our cries.....please

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Jamie Kane Accurate guidelines for the treatment of Lyme and confections put into place as well as educational programs. There are hoards of people needlessly suffering day after day and year after year.

Beth Pattz I would love to know why the admin of this page is censoring all of my friends when we just want the TRUTH about Lyme to be told? THIS IS AMERICA last I checked!

Jennifer Schierholt Please give people suffering from tick-related chronic infections the same care, consideration and respect that you give to those suffering from Hep, TB, STDs and AIDS. Do we need to enlist the help of a celebrity spokesperson before you'll take us seriously? Do what your oath requires you to do. If you are unable or unwilling to do that, please stop hampering the efforts of the other doctors who will.

Dei Waltenbaugh-Bilunka Treatment and Education for Lyme Disease!

Dougy Lymey As a physician who had an engorged tick bite and bull's , and told by an ID,I do not need to be treated because Elisa screen is negative, I feel that IDSA guidelines have created a large number of sick untreated patients who have chronic tick borne disease. This will be recorded as a severe inflexible stance with grave consequences by IDSA.

Brenda King Treat Lyme Disease like any other disease. Also, treat Lyme patients the way you treat others who are battling their diseases. Why would you turn your back on so many people who are suffering day after day, year after year? I watch my sister and her husband fight to get through each day. Why don't you want to help them? It just doesn't make sense?? What really is so scarey about learning about and treating Lyme Disease? So many more questions but will stop for now.

Gary Tracey Lyme disease does exist and has for over Twenty years in Ct. It has taken over Fifteen years for me to get better (not over)Lyme thanks to a "Lyme Disease Doctor" in Ct. Please have the IDSA change and accept chronic Lyme disease.

Martha Price Need we keep repeating ourselves? LYME DISEASE!!!

Debbie Severinson Because of your guidlines, thousands will die and many more will suffer needlessly wiith this extremely dibilitating disease. It takes its toll on a person in every possible way: physically, mentally, emotionally and financially. I beg you to remember the oath you took as doctors to do no harm. You have the ability to help people and save lives. Why do you insist on denying that chronic Lyme is real? why do you allow the political greed of insurance companies to undermine the oath that you took?

Julie Searcy Anderson IDSA: I'm guessing that self-preservation and fear of a firestorm of class action lawsuits is preventing you from admitting that your guidelines are wrong. So, that being said, my plea to you is to make the human and moral decision to admit your mis-steps and help these people. A less bold approach would be to throw your hands in the air and let the people who DO care and have an accurate understanding of Lyme take over. I would take either option at this point.

Christine Keller Maine, I know dozens of suffers here including my brother, and several classmates, and family in MA and on Cape Cod. Lyme folks, post your states/countries so that they hear your nationwide call! This is a national and worldwide pandemic. I equate the IDSA to Hitler and his mass murdering of millions, this is NO DIFERENT! The IDSA is destroying lives and families, and the cause of millions in unneccessary medical bills, family livelihoods lost and people put in poverty, and certainly a multitude of deaths! It is time to end the corruption. NOW. Today!

Ginger Booker Stop telling people Lyme disease only exists in New England. Acknowledge that chronic Lyme disease symptoms have been recorded in some individuals.

Julie Lant Acknowledge the fact that Chronic Lyme Disease does exist and do something about it! People are suffering and need help and when they turn to you, you turn them away! Help end the suffering please. Do you really care what the public says or are you going to sweep this all under the rug like you have numerous other pieces of evidence from before? Prove me wrong and take on the challenge. How can you ignore 700 plus people telling you that something needs to be done?

Karen J Screpetis Update your LYME DISEASE and CO-INFECTION protocols and guidelines to reflect CHRONIC LYME Disease and CO-INFECTIONS? THAT all providers be allowed to enact treatment protocols that vary from your incidious guildlines and that they will NOT be SANTIONED for being LD providers? Go straight to the

Western Blot? Because of the IDSA... and YOUR ancient guidelines... I have permanant neuro damage from Lyme Disease AND co-infections because I already was born immune-compromised and initially was misdiagnosed my NON-LLD providers because of your guidelines? How many Lyme patients must suffer because of your blundering idiocy?

It is NOT ONLY THE LYME tests... BUT the protocol guidelines should check for co-infections at the SAME TIME? I WAS (and still am being) TREATED for Lyme Disease can co-infections; and all the while went untreated for co-infections because of ISDA's ignorance! Non-LLD provider's NEED to have knowledge of the truth of the severity of TICK co-infections AND the chronic disease state. Get real! It 2012 and it is as if you are still stuck in the 19th century. :(

Amy Whatsitoya I would like to see an IDSA with the utmost integrity. Get rid of the members that pander to, and profit from, big pharma/insurance companies. I know medicine is a business, but hurting and/or killing people with tainted Lyme guidelines? Had I had a physician that wasn't afraid of persecution because I was treated properly, I might not be disabled today.

Kelly Patton Nanney IDSA please begin to make changes in how Lyme disease is treated and diagnoses

Teresa Luttrell *I'd like to see IDSA stop working FOR the insurance industry and change your guidelines to reflect the treatment Lyme patients really need. Many have and continue to suffer because of the IDSA. Shameful.*

Todd Alshouse update the Lyme laws!!! the amount of personal friends and family members i have to watch suffer due to the failure to recognize Lyme for what it is is getting ridiculous! Lyme is chronic, and anyone who says otherwise is part of an insurance company.

Peri Merson Satin "When you make a mistake, don't look back at it long. Take the reason of the thing into your mind and then look forward. Mistakes are lessons of wisdom. The past cannot be changed. The future is yet in your power." (Hugh White) Revise the Lyme guidelines. Educate and enable doctors. Get insurance companies to pay for treatment. Raise public awareness. FIND A CURE!

Sylvia Mccartha I would like to see a recognition of the seriousness of Lyme disease among the medical community.

Support from IDSA Doctors and insurance to step up to the plate

Donna Zukaitis Falcone @Christine Keller... good idea! PENNSYLVANIA!

Tracy Hamer Will Please acknowledge that Chronic Lyme Disease DOES exist. Please, please help us and stop fighting against us. We are not the enemy. We are the victims of the leading infectious disease in America today, yet the very international society that is supposed to be on the cutting edge of research, diagnosis, and treatment guidelines is leaving us by the roadside to die.

Our insurance companies won't pay for our treatments because you say we don't need more than a month's worth, despite loads of research disputing this, so we die.

Doctors don't want to treat us because they are shunned, investigated, harassed, and called before the medical board due to your guidelines and top dogs, so we die.

We pay out of pocket to seek treatment because doctors who take insurance end up on watch lists and in front of medical boards, so we go bankrupt and can't feed our children, and lose everything. Or we die.

We don't get diagnosed quickly enough, so there is little hope sometimes for us to get better, so we live with no quality of life, bedridden, disabled, unable to care for ourselves or provide for ourselves, in constant pain and in no end in sight, so we die at our own hands.

You have the power this year to begin the change that would end the endless agony for us. More people are afflicted by this disease than any other disease on your agenda. Help us. HELP US. Make this year be the year you do something to "discover" something new that Chronic Lyme exists if you must to save face. But HELP US. Stop us from suffering, taking our own lives, going homeless, without food, clothes, and living in agonizing pain and depression everyday because NO ONE WILL TREAT US or we can't afford the doctors who will.

This is an atrocity against humankind of the worst degree that has been seen in centuries. You must reach down deep and recognize what you are doing to people and STOP IT. If any of you have a shred of human decency, do what you know you have to do...stop the propaganda, stop working so hard figuring out how to keep the sham going, and just HELP US.

It won't keep going forever. Newer, younger doctors will come on with ethics and consciences and they won't tow the party line any longer. I personally spoke to some of them at your annual conference in Boston in October. This WILL end. You can start off the new year strategizing the best way to end it in your favor. Just end it. We don't care how. We just need treatment. We want the suffering to stop, our children to stop crying, our families to stop suffering.

Neil Huey My wife picked up Lyme and other tick-borne diseases, which turned chronic, in the Outer Banks of North Carolina. Of all places who would ever guess?! But then, the northern most point of Long Island, NY, Montauk, had warning signs posting Rocky Mountain Spotted Fever. I guess those pesky little ticks weren't told to stay in the Rockies. We've got a problem with tick-borne disease folks...continue to speak up or we will never be heard.

Kerri Tolbert Look at the facts--we can get better with treatment. Lyme like Syphillis requires long-term treatment!

Donna Zukaitis Falcone Christine had a great idea! "Lyme folks, post your states/countries so that they hear your nationwide call!" Where are you from?

Tom Easton I'm another Lyme sufferer who is recovering nicely and nearly back to normal after treatment from a Lyme Literate Doctor. The IDSA affiliated infectious disease specialist that I previously saw told me I was adequately treated with 3 weeks of Doxycycline and that I had my continuing lethargy, brain fog, and arthritis was "post Lyme disease syndrome". I hate that doctor for wasting years of my life thinking there was nothing that I could do.

Kathleen Dickson I would love for someone at IDSA to explain to us what OspA was.
http://www.actionLyme.org/
120102; Lamestream News (WaPo) reports that Lyme and LYMErix are immunosuppressive.
www.actionLyme.org

Make a TLR2 agonist bot so we can do away with ticks-and-fungal- immune suppression.

Kristie Lohrer Huntsville Alabama

Robin Steward Like so many others, my teenage daughter has suffered and gone undiagnosed and untreated for many years in Oklahoma. Acute and Chronic Lyme disease are real! and need to be recognized by the mainstream medical community. It is a shame that my daughter has had illness after illness and significant chronic pain that potentially could've been shortened or prevented if this disease was recognized and tested for properly! It is also unfortunate that insurance rarely pays. All of this can be changed if you take steps to make it happen! PLEASE HELP!

Tara Hulko For the IDSA to look at the ILADS research for Lyme Disease. I would love to see better testing. I was left ill because I had a coinfection of bartonella that turned off my antibodies for a positive Lyme test leaving me unable to be treated and I was left disabled for a long time till I paid out of pocket for treatment. The guidelines and testing are flawed and people are becoming disabled and dying. Once upon a time HIV and AIDS were the Lyme Disease of today. Most of us are not asking for radical treatments- but to allow doctors better education and testing- what you have is outdated. If medicine isn't allowed to evolve- we would still be blood letting for cures.

We need a focus on Lyme Disease- my state of Pennsylvania is now #1 for cases- it's only getting worse, not better. Especially with the ticks in 2 birth cycles- making Spring and Fall high risk. And not just Lyme Disease but the Co-infections are most times worse then the Lyme. Examples are bartonella & babesia for example. I still live with the damage done to my body and live in severe pain and fatigue and suffer from tremors from my ruined nervous system- all because my doctor couldn't treat me properly. Oh did I mention my 87 THOUSAND DOLLAR Heart Surgery?!?

Kelly Patton Nanney Both our children have been sick for 5 years. we have spent so much money, it is unbelievable!!!! They are getting better but it is because we have become medical experts ourselves to ensure they continue to make progress. It just doesn't seem possible that we could have insurance, pay our premiums and then be denied at every turn. hundreds of thousands of dollars when you are talking about 2 children being sick. Almost everything out of pocket, iv's, perscriptions, injections, supplements, etc.

My husband and I have a fairly successful drapery [kellysdesignerdraperies.com] but we could never make the kind of money that it cost to keep our 2 kids getting better. We had to move to another state in which they both had picc lines and recieved iv infusions for 7 months. IDSA if you are reading just imagine how this would affect any family. Thankfully my husband and I are still together and not giving up but we are way out of money and at some point will have to lower our standards even more than we already have. Please be willing to go back to the drawing board so that families like ours can get some support that will somehow influence our insurance company to step up and reimberse us for all that we have spent. I know I am talking about money but it is such a contributer to the pain and suffering. We live right next to St. Jude where no child is ever turned away for cancer treatment because of an inability to pay. Such a slap in the face when we have watched our kids lose stamina and endurance to live life.

Theresa Briccetti I would like to see Lyme Disease treated like all other chronic diseases. I would like the IDSA to acknowledge Chronic Lyme Disease does exist. I invite any member of the IDSA to spend a day with my husband and then tell me that Chronic Lyme does not exist. The last three years have been a nightmare. We never saw a tick, he never had a bulls eye rash, he never had 'flu like symptoms', but because of Lyme Disease his life has been drastically changed.

Kathleen Dickson IDSA doesn't admit what TLR2 agonists like OspA or LYMErix does to the immune system - like activate Epstein-Barr.

MaryLee Seaman changing the guidelines for Lyme disease so it can be diagnosed and treated in a more adequate manner.

Kathleen Dickson ILADS does not know what they're talking about, so they're no help, either. The latest news that slams IDSA is the fact that MRSA biofilms are covered with LYMErix.

Teresa Luttrell I'd like to see IDSA stop working FOR the insurance industry and change your guidelines to reflect the treatment Lyme patients really need. Many have and continue to suffer because of the IDSA. Shameful.

Sue Darms A more enlightened attitude about Lyme, instead of just writing us off when we don't get better after a couple of weeks.

Debbie Severinson Austin, Texas. yes, we do have Lyme in Texas!

Jennifer Schierholt Southern California

Diana Giffin New guidelines and open ended rules for Doctor's who are willing to treat patients for Chronic Lyme disease which I caught in Northern California. Open ended treatment for Lyme disease should be at least considered given its success in many patients.

Denise Bojczuk Thank you Tracey Hamer Will! You said it so well I am going to post again.

Please acknowledge that Chronic Lyme Disease DOES exist. Please, please help us and stop fighting against us. We are not the enemy. We are the victims of the leading infectious disease in America today, yet the very international society that is supposed to be on the cutting edge of research, diagnosis, and treatment guidelines is leaving us by the roadside to die.

Our insurance companies won't pay for our treatments because you say we don't need more than a month's worth, despite loads of research disputing this, so we die.

Doctors don't want to treat us because they are shunned, investigated, harrassed, and called before the medical board due to your guidelines and top dogs, so we die.

We pay out of pocket to seek treatment because doctors who take insurance end up on watch lists and in front of medical boards, so we go bankrupt and can't feed our children, and lose everything. Or we die.
We don't get diagnosed quickly enough, so there is little hope sometimes for us to get better, so we live with no quality of life, bedridden, disabled, unable to care for ourselves or provide for ourselves, in constant pain and in no end in sight, so we die at our own hands.

You have the power this year to begin the change that would end the endless agony for us. More people are afflicted by this disease than any other disease on your agenda. Help us. HELP US. Make this year be the year you do something to "discover" something new that Chronic Lyme exists if you must to save face. But HELP

US. Stop us from suffering, taking our own lives, going homeless, without food, clothes, and living in agonizing pain and depression everyday because NO ONE WILL TREAT US or we can't afford the doctors who will.
This is an atrocity against humankind of the worst degree that has been seen in centuries. You must reach down deep and recognize what you are doing to people and STOP IT. If any of you have a shred of human decency, do what you know you have to do...stop the propaganda, stop working so hard figuring out how to keep the sham going, and just HELP US.

It won't keep going forever. Newer, younger doctors will come on with ethics and consciences and they won't tow the party line any longer. I personally spoke to some of them at your annual conference in Boston in October. This WILL end. You can start off the new year strategizing the best way to end it in your favor. Just end it. We don't care how. We just need treatment. We want the suffering to stop, our children to stop crying, our families to stop suffering.

Beth Pattz Family of 4 from Central Illinois with Borrelia, Babesia & Bartonella.

Wrblr Fvtwlv The members who "represented" IDSA in the Blumenthal panel should be stripped of that membership and the Lyme guidelines overhauled. The general drop in antibiotic effectiveness, the subject of half your Facebook posts, is occurring whether Lyme patients get prolonged treatment or not, and yet, these are the tools we have for now. Doctors should not be witch-hunted for using them while better tools are developed. Those current members who've saved insurance companies millions denying treatment for "post-Lyme" have cost the country millions more in productivity and caused a level of suffering your "concerned" leadership is personally unfamiliar with or perhaps just too afraid to acknowledge. It's is no wonder the public trust in federal health agencies over vaccines or anything else has plunged.

Mary Bush *What IDSA fails to recognize is its growing obsolescence. Lack of treatment for patients with infectious diseases, well within the scope of IDSA, now all called "Lyme disease," are actually several diseases that are treatable at early stages. Guidelines from IDSA have made that treatment impossible, and so we see a growing body of science, research and clinical, moving to a new standard of care--a much, much better one. Not available to most patients, however, so most are left to fend for selves, die, or commit suicide. Shame on IDSA.*

Kathy White If you can't find a cure for Lyme disease please, please, please help to stop the persecution of doctors treating people who have Lyme disease!

Josh Cutler Like previously stated list where you contracted Lyme disease.

I got Lyme disease in ashburn, va where the local health dept has called loudon county an epidemic area for Lyme disease. Rep. Frank Wolf is battling for us. Any google search of the are will yield article after article on the battle of Chronic Lyme.

Nicole Lyons Johnson More education and research on treatment. Have been fighnting chronic Lyme disease for over 2 years. I knew nothing about Lyme disease prior to this getting it in 2009. Please acknowledge that it IS the fastest growing infectious disease. There is so much education and awareness about about West Nile and I have never known anyone who had this. I know many suffering long term with Lyme disease.

Jessica Madson Please acknowledge Lyme as a serious disease affecting hundreds of thousands of people if not more. Change the guidelines so there is better diagnosis and treatment. Doctors shouldn't be afraid to treat patients as they see fit and insurance companies need to cover the cost.

Gayle Link My first symptoms were after several tick bites as a child in Missouri, then re-infected after a trip to Yosemite... adding babesia and bartonella to the mix.

Renee Pearsall Wake up IDSA. Most of you know in your hearts that Chronic Lyme exsist and is destroying the lives of thousands of people everyday. You are just too afraid to take a stand and buck the antiquated and out dated guidelines that you have created because of your own ignorance. My daughter was sick for 10 yrs before we finally found an ILADS doc in NY who properly diagnosed her and didn't tell her that she was just sick because she wanted attention or it was all in her head. It has been almost 3 yrs of docto visits paid out of pocket, medicines paid out of pocket and other doctors who have shuned us because we have spoken up about Lyme.

Stacy Hughes Rolland role of biofilms in chronic disease

Carl Stancil How about POSTING a PUBLIC RESPONSE right here on this page to all of these comments?!! Show us you actually CARE about getting our opinions since you ASKED FOR IT!

Kathy Obal Carlstrom A physician with Lyme disease ("Lyme complex" is probably a better term) shares his testimony about what happened to him after being given a short term course of antibiotics and then denied further antibiotics. In many cases, Lyme complex simply cannot be treated in 4-6 weeks. Each person requires a unique treatment time, from many months to often many years. A definitive time frame cannot be put on any individual's treatment course.

There are simply too many factors that effect each person's recovery time such as; acute opportunistic infections, systemic yeast/molds, surgery interrupting treatment progress, antibiotic resistant strains, treatment failures requiring the patient to try multiple treatments until they find one that works, germs that adapt and require the switching of medicine, multiplicity of infections that need to be addressed, etc. Such needs to be considered and become the accepted and humane "standard of care" among the medical community. Thank you for listening to my thoughts today.http://www.youtube.com/watch?v=EwW0-ky7DdY&feature=plcp&context=C3555110UDOEgsToPDskIbSL_rIun5P-AK2feOCtb-

Heather Sammut If you refuse to recognize that we all have chronic Lyme then you should be doing research on what it is we are all suffering from because it is an EPIDEMIC!

Nancie Brengle Wow!! 751 comments…… My little family of 5 has 2 members with Lyme!! 40% of mine is suffering with this. Myself and my 4 year old. What would happen if a patient tested positive for cancer and the doctor said, well I think that is a false positive so we are not going to treat? The patient would then go on to get worse and worse. Imagine hearing Nope, we are not going to treat you!! I tested positive CDC positive for Lyme and thats exactly what I heard. I grew up hearing that America was the best place on earth. A place where dreams come true, a place where you could be whatever you wanted to be.. You know what I want to be?? HEALTHY!!! I want my child to be healthy. Knowing you are suffering and realizing there is nothing anyone will do to help is the most hopeless feeling you can had.. And you know what.. You guys have the power to change this.. The ISDA has the power to make a difference in the world, to make a difference in the lives of so many suffering people.. To be the Hero's.. I am not sure how all of you grew up, but I grew up being taught that making a difference and helping those who could not help themselves is the kind of person we were all supposed to be!! Will you be those people?? MAKE A DIFFERENCE ISDA... SAVE A LIFE STARTING TODAY!!!

Kara Rose please begin to make changes in how Lyme disease is treated and diagnoses

Caity Boyd I am 17 years old, and have been sick for over a year with Lyme. I have lost everything. my life. my friends. my freedom. and most importantly my health. My parents have spent thousands of dollars going from doctor to doctor, we have to travel out of state to even see a doctor who will treat for Lyme. Lyme is worse then cancer because it is always changing, and for you not to even recognize it as a disease, that's just crazy. People are asking for help. begging for help. PLEASE help them. Lyme is real. and it is destroying the lives of many people.

Katrina Muysenberg I would love it if the IDSA and others in the medical community stopped denying the existence of Chronic Lyme disease. It is real. And it is a serious problem for those who suffer from it. Acknowledge the fact that it is real. Please.

Mary Bush What IDSA fails to recognize is its growing obsolescence. Lack of treatment for patients with infectious diseases, well within the scope of IDSA, now all called "Lyme disease," are actually several diseases that are treatable at early stages. Guidelines from IDSA have made that treatment impossible, and so we see a growing body of science, research and clinical, moving to a new standard of care--a much, much better one. Not available to most patients, however, so most are left to fend for selves, die, or commit suicide. Shame on IDSA.

Mary Bush IDSA's abrogation of responsibility in so many directions points to a failed system. A tick bite can and will soon affect enough in the IDSA family itself, that the answers will come. Too late for us, but they will come. So what do we want this year? I'd like to see IDSA shut down, or investigated.

Anna Rose Please modify your Lyme and coinfection protocols. Late stage/chronic Lyme DOES exist. Why do you continue to deny this. If you or one of your family members suffered from it, I think you would feel differently.

Sarah Steinmann Please recognize that fact that Lyme disease is real. Thank you!

Deal Yeti 1) Add the specific and significant bands removed for the recalled human Lyme Disease vaccine back into the Western Blot test: 22, 23, 25, 31, and 34, which include OSPA, OSP-B and OSP-C antigens - the three most widely accepted and recognized Bb antigens.

2) Discontinue reliance on the notoriously faulty ELISA test for Lyme, which has proven in blind studies to be less accurate than flipping a coin!

3) Research additional vectors for Lyme Disease – including other bloodsucking insects (since the cat flea, for instance, has been identified as a carrier for the Borrelia burgdorferi) and its possible status as an STD (since Lyme is a relative of syphilis and there is a higher incidence of Lyme in married couples).

4) Acknowledge that the absence of a bulls-eye rash is NOT the absence of Lyme.

5) Acknowledge that people can be infected by tick nymphs, which are the size of a poppy seed and have a painless bite, so not remembering a tick bite does NOT = not getting Lyme.
6) Acknowledge that Lyme is widespread throughout the country, so simply being from a certain state doesn’t mean you don’t have Lyme.

And overall: Release your death-grip on your antiquated Lyme Disease guidelines in the face of a growing body of evidence (from doctors and patients alike) showing how inaccurate they are. The current IDSA guidelines amount to systemic malpractice and the IDSA’s fanatical adherence to them is both shameful and unethical.

Alicia Meadows-Haney Treatment and education for Lyme disease! My husband was bit by a tick and tested positive for Lyme. We did the 3 week antibiotic and was told everything was fine. After a year of chronic pain we found out he had 2 other co-infections that never got treated, and he still had Lyme. Now this disease has had a year to imbed in his body. He can't function or work without ridiculous amount of antibiotics that he takes daily. This could have been avoided. This is an epidemic and needs to be taken seriously.

Angel Williams Spell I just feel overwhelmed because here i am fighting this daily and watching my seven yr old suffer from it and possibly having infected my whole family and not only is that a DAILY battle, but knowing that my rights have been infringed upon and having to fight just to have treatment is too much to bear.....i feel like i have been wounded on the battle field and my superiors instead of dragging me off the field, they have left me there to defend for myself, and dont even believed im injured.....i truly feel betrayed by the very ones who took an oath to protect us...why?.....why have u left us here to suffer and battle alone?....we are fighting A KILLER and you would rather tell us that killer doesnt exist even though you have seen us die but you would rather claim its 15 other diseases....and we r begging for help....some of us are financially broke because of this.....WE HAVENT ASKED ANY OF YOU TO LAY A GOLDEN EGG....so therefore just caring about us is something U CAN DO.

Heather Sammut Central California

Susan Anderson I want you to acknowledge the existence & need for identification and treatment of CHRONIC LYME DISEASE! I know I have it, and many, many others who need treatment but cannot get it. C'mon, wake up!

Laura Abramson Me and the hundreds of thousands of other chronic Lyme sufferers NEED better treatment plans, medications, insurance coverage along with more education given to the public. EVERYONE needs to know how very REAL and SERIOUS this horrible disease is and all of the physical and mental reactions we all suffer through. Please stop hiding the reality of LYME Disease. It is everywhere and Doctors and the public need to KNOW IT.

Lizzy Cocks Coverage for my family's Lyme medicines please!

Mary Bush Redefine "Lyme" and call it what it is--or is not: Borrelia, Bartonella, Babesia, and more. Stop letting patients wonder what is wrong with them, acknowledge new testing, do state to state trials, remove the "we don't have it in this state" idiocy (i.e. expand geographic ranges), include physicians who really are successful (though I doubt they'll work with IDSA at this point), get rid of current leadership, and talk to patients. That's just for starters. Patients have a LOT of misinformation and stick by that, because they have nowhere else to go.

Stephanie Vandagriff We will not be ignored! Everybody keep contacting news stations to get this story heard!

Suzy Greenberg I'm tired of fighting this disease and need you on my side. We have an epidemic going on here and feel like we're talking to deaf ears. We need our doctors to be educated on Lyme and co's so that the next generation of people getting bit won't have it turn into chronic Lyme like I have. We seem to be doing more of the research than you are and it doesn't make sense that you aren't doing the same if not more. I beg of you...please help us!

E Louise LaManna Treat chronic Lyme disease like the epidemic it is. And find better testing for Lyme.

Janet O'Lacey *Integrity*

Beverly MacDonald Baker *I would like research to find faster, accurate testing. I would like the IDSA to acknowledge that chronic Lyme exists. Inform our doctors about Lyme so they will test without being asked to, when symptoms are present.*

More research to find out what will cure Lyme/Chronic Lyme and allow those Drs to treat chronic Lyme.
Those of us with Lyme/Chronic Lyme are getting better informed, better organized and WE ARE NOT GOING AWAY.

Julie Searcy Anderson Southeast Texas

Angel Williams Spell North Carolina

Hannah Hollingsworth I would like a shift in IDSA's loyalty. I'd like to see more of an emphasis on patient well-being and public health than on writing guidelines in legalese language that emphasizes ways for insurance companies to deny care to patients. I was tested using the Igenix lab company and found to be positive for both acute and chronic borellia burgdorferi, a finding that would have shown as a negative using the widespread, yet totally insufficient testing that most MD's use.

I would like to see the Infectious Diseases Society of America be primarily interested in supporting people who have infectious diseases of epidemic proportions in America - notably Chronic Lyme Disease. There is a wide body of medical literature showing that the borellia spirochete can hide from antibiotics and the immune system - simultaneously. Thus, the recommended guidelines are insufficient in treating many patients. Please consider that all us 'Chronic Lymies' aren't just lying.

Isaiah Goodwin So many whole families struck together with Lyme regardless of where they live. Seems a bit odd to me if you say it cant be transmitted other ways than ticks. Although studies prove its found in sperm, vaginal secretions, placenta, breastmilk and even saliva. With our animals horses, cows, chickens being tested with a 90% positive outcome of Lyme. What does this mean in our food supply? Raw meat= Lyme, egg yolk=Lyme, lick from your horse Lyme, hunters getting Lyme, blood transfusions need better guidelines if a person has ever had Lyme disease they should never ever give blood to another human being. 30 days of antibiotics is the guidelines my testing just got going after 6 months of treatment the testing shows more positive bands. Spider bites, fleas and more can spread this and no talk at all about the co infections that are almost worse as the Lyme disease itself.

Daniel Andrés Patiño some guts and heart from its directives.

Bree BreeZerker Harrison Admit there is chronic Lyme, admit there is Lyme in Tx. allow people to be treated as long as neccessary, don't run out the doctors that do treat long term, require doctors to test for Lyme especially if chronic pain has existed for years without explanation or began with illnes exp. meningitis...
I've been sick since 2001, I was tortured for 5yrs by a pain dr that I begged for testing for Lyme, Lupus & RA, I had every expensive interventional treatment they could come up with up to/including Morphine pain pump that failed 3x due to muscle

spasms tearing the catheter out of my spine.

When after 2yrs of catheter failures I asked for the pump to be removed (8yrs sick, 5 with this pain dr who required me to see his mental therapist) I was told "it's all in your head" then same dr had me on required zoloft & elavil put me on Savella sample pack & didn't take me off of the other ssri meds, I ended up with seratonin sickness until I looked up savella & learned that he did wrong yet again. I quit that dr immeadiately & found a good dr that actually pointed out that my mri results showed I should have been sent to infectious diseases dr bc there was something in my bone marrow that was showing illness, that info was kept from me & the pain pump, I was told, was my only chance for relief.

I trusted this doctor completely & my care was not done in the best interest of my health or recovery, instead I was used to get every penny that I had & then when they did wrong they tried to make me sick with combining meds that shouldn't be combined. why is this allowed???? if this happened to me how many has this happened to or worse????

Missy Smith Griffin Jefferson South Carolina. Please don't ignore us any longer. We need your help. Would you ignore someone with Cancer? Lyme Disease is real. If you could walk in our shoe just one day. You would feel our pain.

Peter Kemp Whether the IDSA like it or not, many people in other countries look with hope to the USA for scientific and medical progress in diagnosing and treating Lyme disease. Their hope may prove well-founded thanks to some brilliant researchers and dedicated physicians – but this is no thanks to the IDSA.

When I watched the webcast of the review of the IDSA Guidelines for Lyme Disease, I was struck by the convincing evidence and sound reasoning of the physicians and scientists that believe Lyme disease can be chronic. But it’s as though the IDSA were not listening because the guidelines remained essentially the same. It seems they simply ignored this evidence and this has continued to leave desperately ill people struggling to get treatment.

How many people have been unable to find a physician willing to treat their chronic Lyme disease because of the IDSA guidelines? How many have to travel great distances to see a doctor, if they can manage and if they can afford it? How many are waiting years for a diagnosis, perhaps with every month that passes increasing the risk that their infection will become intractable? Can the IDSA answer these questions?
I can understand that the IDSA do not like being attacked, but from a chronic Lyme perspective; we watched fine scientists and physicians addressing the IDSA and it seems their evidence was simply ignored. Are we going to be listened to if we calmly ask for better guidelines? It required legal action to get the IDSA to do the last review, will you do another review if we ask nicely?

Pretty Please.

Josh Cutler What must we do IDSA? We are sick, tired and feeling like we can hardly keep pushing.
Do you want us on our knees begging for the truth and a change in front of your HQ in Alexandria, Va?
We are people with families just like you. We only have this one life and we want a fair chance at being happy just like you guys.

Jennifer Schierholt Individuals with chronic Lyme and co-infections aren't the only ones who are suffering. Spouses, children, whole families, employers, and entire communities suffer when medical professionals insist on ignoring evidence of emerging infectious diseases. Did you learn nothing from the 1980's? Please don't let the band play on with this one, too. Please do the right thing. You know you can. Please help.

Yvonne Forey Please dont forget us in the UK ...if anything does change we will have to wait years for it to pass over here too..just like AIDS ..many people i know are reading this and probably think its only USA and overseas....as stated before, we have NO doctors who will treat, NO insurance and NO ONE to take us seriously unless we fly (too sick and no funds) to other countries like yours..My son drove me to Germany I came home as bad..little did we know then he and most of the family, grandchildren etc had it too....When you decide to delete this thread without giving us any answers...sleep well but dont forget to wash the blood off your hands of hundreds of thousands of sufferers WORLDWIDE! who just want the rights we deserve.. at the very least for you to admit your wrong...one day you will come to us for help when your dying...I know many of us would help you...help us

Kathleen Dickson You all should be asking IDSA what OspA is. If they answer it honestly, they self-indict for FRAUD and HOMICIDE, LOL.

Kathleen Dickson They can't answer the question, "What were those vaccines, ImmuLyme and LYMErix?" without turning themselves in to the FBI for scientific fraud and racketeering. And homicide.

Josh Cutler Kathleen we are all sure their hands are dirty. I don't care if they admit they were wrong. If we accuse them and try to hang them for past crimes it will back them in a corner.

I forgive whatever it is they did. I just want new guidelines an research towards a cure.

Janet O'Lacey Integrity

Beverly MacDonald Baker I would like research to find faster, accurate testing. I would like the IDSA to acknowledge that chronic Lyme exists. Inform our doctors about Lyme so they will test without being asked to, when symptoms are present.

More research to find out what will cure Lyme/Chronic Lyme and allow those Drs to treat chronic Lyme. Those of us with Lyme/Chronic Lyme are getting better informed, better organized and WE ARE NOT GOING AWAY.

Donna Lee Williams Please revise your guidelines according to the newest research (it doesn't have to be IDSA research). Admit that Lyme disease can be chronic. So many people in the real world are suffering Lyme's horrible symptoms and unremitting pain. We are not all hypochondriacs. We unerstand that there are risks to taking antibiotics long term but the decision should be ours. Find newer better tests for Lyme disease. Think out of the box when it comes to research. I developed neurological Lyme in 2001. I never saw a tick or a rash. It wasn't until I began a combination of drugs that I began to get better at all. After four years of being bedridden and house-bound, I began to get well. Today I am about 95% better. I thank God that my IDSA doctor allowed me to stay on antibiotics until I got well

Kimberly Aldrup-Otto I lost my job, home, EVERYTHING to Lyme. My 3 year old is infected still no treatment for him and suffering.... And, for what? Because the truth has been denied to all of us. How can a disease be around for 40 years, and than some if the truth was really told, and we are still being denied???? Answers would be nice as human beings.

Lydia May Clark from Warwick, Rhode Island, one of the few states to have a law mandating certain insurance companies to cover all treatment for chronic Lyme. I'm in an endemic area and it still took me at least a year to be diagnosed (not sure when I was infected, but I could hazard a guess). This disease almost ruined my life; thank goodness I found a doctor who didn't attribute my severe, widespread encephalopathy as observed on my SPECT scan to the delusions of a silly teenager with deep-seeded psychological issues.

What would I like to see change in society? How about doctors that don't write off patients as insane rather than admit they're too lazy to look for a correct diagnosis? How about doctors who actually look for horses (Lyme disease) before zebras (MS, ALS, "complicated migraines", "idiopathic movement disorder", conversion disorder, etc.)? How about we scrap the IDSA guidelines and start fresh? How about an IDSA panel made up of honest doctors, not greedy pigs in big pharma and the insurance companies' pockets, or biowarfare experts (we're onto you, Wormser)? How about a panel with real experts with experience fighting Lyme in the trenches like Jemsek and Burrascano, not self-important, self-serving academics? How about research into more accurate blood tests? How about more doctors ordering SPECT scans to rule out encephalopathy before dismissing a patient as nuts? How about you stop minimizing chronic Lyme as the "aches and pains of daily living" and ignoring those of us who have lost the ability to walk, talk, and have control over our muscle movements and bodily functions due to this terrible disease?

How about more doctors who care about their patients, not the establishment? How about doctors who are free to treat their patients with long-term antibiotics (like they do with related diseases such as syphilis and relapsing fever) without fear of losing their jobs? How about insurance companies covering our very expensive treatment without the state government mandating them to? Even with insurance covering it, my Lyme treatment has cost more than my late mother's cancer treatment. If we had to pay for that out of pocket, my family would have lost our house and my siblings and I would have kissed our aspirations to go to college goodbye. That is not okay.

I could go on, but others have said what needs to be said. Sorry for any grammatical or spelling errors in the post. My Lyme is affecting my left posterior temporal lobe the most, and I still haven't gotten back to my old self yet.
Greetings

Hootan Veeh The problem the way I see it is that the vast majority of Lyme patients don't even bother to see IDSA infectious disease doctors. That is just sad.

Katie McGrath This year I want to see the guidelines changed for Lyme disease so it can be diagnosed and treated.

Jenna Leigh one of my best friends has Lyme. please please knowledge it. She has to go out of state to go see a doctor. Which just stresses her out even more making the lLyme even worse.Shes in constant pain . I dont know how people can say shes making it up, when you can clearly see the pain in her eyes. I just want my best friend to get better. please regonize it and help. it is real.

Michelle Kopp Tracey Hamer Will: everything I wanted to say and more. Kudos.

Gary Simmons It's one thing to be sick with this vector borne spirochetel illness and fight for your life but to have your narrow minded self centered view makes my blood boil. My wife, my 2 sons and I have been battling this illness since 1989 and your view points led our physicians to build a super bug in us. Wish I could really tell you what I think of your organization.

Jeff Rainey *I would like to see movement towards a cure and less prosecution of those that try to cure! This disease is destroying families by the score. It is bankrupting thousands.*

Bill Barber IDSA's credibility is under fire and rightfully so as they continually ignore the overwhelming evidence of chronic Lyme disease and the fact that Lime disease is an epidemic that is spreading across our nation. The archaic and flawed Lyme disease treatment guidelines that prevent knowledgeable doctors from treating this disease are harmful and must be revised. The frontline fighters of Lyme disease are getting hammered from the people that should be encouraging and helping them. How many more families must suffer because of IDSA's failure to act responsibly? How many more must die before IDSA finally gets it.

Taylor Derrick Recognition of Lyme Disease and for the society to stop making it so hard on doctors who choose to treat it. (Central Florida)

Puma Of-Thenorth Face it the Attorney General of Conn. had the IDSA's number correct a long time ago. They are basically more interested in greed than helping the people whose tax dollars pay their salaries.

Laura Hoffert I would like to see, in the very least, an acknowledgement of Lyme disease's existence. The majority of replies to the IDSA's post are about Lyme, there are people suffering due to organization's ignorance to a major medical problem. It's vital to people's health and vital to the organization to maintain a shred of credibility.

Jason Hulko I would like to see the IDSA not blanketly throw out research presented before the respective panels. If medicine had always turned a blind eye to the possibilities laid out before it through legitimate private research then rabies would still be killing a lot of people. The IDSA needs to accept and review all research. Not just research done through selected sources.

Jeff Rainey I would like to see movement towards a cure and less prosecution of those that try to cure! This disease is destroying families by the score. It is bankrupting thousands.

Jan Orf Still sitting here in Missouri 4 years later with the swelling and pain in my hands and knees that the IDSA specialist called "depression" even after he admitted I had a positive Lyme test. This is not an exageration. My husband was an incredulous witness to this conversation. If I had received the proper treatment in the beginning, perhaps I would not still be suffering. Thankfully I eventually found an ILADS doctor who continues to help me improve. Please, IDSA, if you cannot open your eyes to seek the truth and prevent more suffering, then just be silent and let ILADS and it's doctors do their work.

Charlene Libby I'd like to see a focus on testing, diagnosis and treatment of Lyme disease. The medical community seems to need more validation of the seriousness of this condition. Many people are suffering.

Kathleen Goll-Derstine Thank you for asking this question and listening to our input. Please review and revise your guidelines for Lyme disease and tick borne illness. We patients need research into more accurate testing and effective treatments, not more bickering. In 2004 I saw the head of infectious disease at a well known N. CA clinic, who, when I asked about the possibility of Lyme, had at the ready, copies of NYT articles to the effect that chronic Lyme could not exist and testing for it is a scam, the position if ISDA. Was also told that Lyme infection did not exist in CA.

This is all very irrational, as there is plenty of peer-reviewed research to the contrary. Please, take into account patient's viewpoints and the many areas of research that call your current guidelines into question. I could have gotten help much sooner...this doc had nothing to offer me but symptomatic relief. This would be unconscionable for any other serious illness, "Lyme" and tick borne illness prevalence is only going to continue to grow--will the IDSA band play on?

Dani Spirer An acknowledgement by the IDSA that chronic Lyme disease does exist and that Lyme disease for many many people is NOT hard to get and easy to cure - it is an insidious, growing epidemic and should be treated as such.

Anne Graves My best friend and little sister has been fighting Lyme disease for the past year. I'd like for her struggle to be recognized, and for her fight to be easier. Don't make her leave the state to find treatment, let her stay close to her friends and family who love her and support her. Please acknowledge her sickness and help her recover. Ignoring it won't make it go away.

Jessina Bereznak In some ways, I feel grateful that I now know what is wrong with me. I KNOW I have Lyme. I've been in the fight of my life for the last 2 years and am almost 100% (with no help from mainstream medicine or insurance). I had been sick with various problems for 16 years. Two years ago, I was looking at "MS". How many people out there are misdiagnosed with these "idiopathic" diseases and really have Lyme? How many decline even further into disability from the immune suppressive drugs they are given? I'd bet world wide, it is millions. Your guidelines are causing the suffering of not only the known Lyme community, but all of those who are misdiagnosed with so many diseases that Lyme "mimics" who were not fortunate enough to have proper testing.

Denise Weaver please do not let us die....LYME is spreading.

Heidi Teff Ehalt Acknowlege existence of Chronic Lyme disease! With so much controversy and evidence, how could and why would anyone proclaim definitively that it didn't exist?

Juliana King You asked we are answering. Please acknowledge that this disease is taking away our lives and killing the people we love. I have been bed bound for 18 months and have watched countless friends suffering with very little or no help. Please open your eyes, please reach out. Please care. What if this was your daughter, your mother, your wife, your friend. We need treatment, we need a cure, we need doctors, we need medications, we need awareness. We need you. Please don't give up on us.

Don Knieriem I suffer from chronic Lyme disease and got much sicker because of the IDSA Lyme disease treatment guidelines. I had to find a secret doctor willing to treat me outside your guidelines. Soon after starting his treatment I began improving and am 99% healthy now. I want you to TALK TO THE DOCTORS WHO KNOW HOW TO TREAT LYME DISEASE AND CORRECT YOUR GUIDELINES!

Kristi Linn Please take Lyme treatment seriously! This disease takes a person's life away from them!

Gail Sheffer When is World Lyme Day? What are you doing to spread the awareness of Lyme and other tick borne diseases???

Crissy LaBruzza I don't really see how this is going to work. These are the same people that tried to stop Under Our Skin from even being shown on PBS. But I do, in my heart, hope someone listens. What's it going to take, every member of their family and children to get Lyme disease, like so many of us? It amazes me that these bacteria have been evolving to evade our immune systems for thousands of years, yet some think that just because a mediocre, run-of-the-mill test someone spent a few years creating can't pick it up, it mustn't be there. How arrogant.

Derek Springsteen the recognition of chronic Lyme disease as a serious condition that must be further studied by the medical community in order to discover and develop proper treatment.

Richard Shelley We have the technology in this great country of ours to come up with a cure for Lyme disease. Why won't anyone take the reins and run with it? All the genious scientists need to put their heads together and put an end to this ongoing constant disease which is a battle that never ends. After 5.5 years, 3 different IV courses and a multitude of antibiotics, my body is slowly but surely being destroyed by this disease....come on IDSA, STEP UP TO THE PLATE with some new science already....This Lyme is out of control, I hear in GERMANY they are curing this disease with controlled body temperature risings, why can't we investigate this here in the U.S ??.......Thanks

Sarah Elliott If there are 800 + people who are commenting on their experiences with Chronic Lyme and the CDC estimates that the actual number of people with Lyme is 10 times more than reported, you're looking at at least 8,000 people with this disease. That is not taking into account those who aren't up to speaking, aren't on facebook, etc.

In addition to what everyone has already said (admittedly, I have not read through all comments), I personally would like to see a strong re-evaluation of IDSA's position on Lyme.

How long did it take to determine how serious HIV/AIDS is? Wouldn't the IDSA prefer to be proactive rather than reactive and not repeat history? It seems to me it'd be more beneficial to all involved if the IDSA were able to take more of a "Pioneering" approach by
1) admitting they've been wrong, 2) interviewing patients, doctors, family members and friends on what our lives are like, 3) understanding that the majority of us are making informed decisions when it comes to treatment (for us the risk of using long term abx is worth the potential to gain our lives back), 4) paving the way to more research, 5) apologizing to not just the patients but also the physicians who've lost their own livelihoods because they chose to answer our pleas to help us get well.

Most people who do not have Lyme wouldn't last an hour in our bodies without running to the nearest emergency room for help. And the emergency room doctors would treat them as if they're hypochondriac drug addicts.

We understand you want to protect the people. But obviously (based on all of these comments) the way you're going about it is ineffective and counter-productive.

I've had Lyme all my life. Was only diagnosed a year and a half ago. Symptomatic since I was 7 years old (if not earlier, that's just my earliest memory of symptoms). I've been disabled for more than 2 years now - often times not having the ability to dress myself, brush my teeth or take care of other basic tasks. If better education & guidelines were in place then perhaps your son or daughter will not experience what I and so many others have experienced.

Denise Weaver Help us to understand why you chose to claim that there is no such thing as Chronic Lyme Disease....my goodness....how can you do this to your fellow human beings...gosh....I sure do not hope this happens to any of you or your children...Denise Weaver in HERSHEY,Pa.

Toni Hothan Recognize both Lyme and Leptospirosis for the epidemics they are - get doctors educated in the diseases and how to treat them, rather than having them continue to insist on trying to treat us with expensive drugs for illnesses we DO NOT have, simply because they know nothing about what we DO HAVE..

Donna Smith O'Hearn You must inevitably admit that Lyme and other tick borne diseases are a serious threat to public health. Why not just do it and get on with helping to heal the afflicted and preventing these diseases?

Lara Scharp In the coming year I would like to be able to recommend people see an infectious disease doctor for Lyme and co-infections instead of telling them to steer very clear of them because they don't know how to treat, use poor guidelines and tell people they have something else or it is in their heads or it is just aging. Unfortunately, I think it will take many years for IDSA to face reality and start treating properly.

Mary Bush Lara, well said!

Beverly Reimers It's so hard to believe Doctors don't recognize Chronic Lyme disease for the horrible, life-consuming problem that it is. My precious 17 yr. old granddaughter was diagnosed with Chronic Lyme over a year ago. They couldn't find doctors in Texas or Oklahoma that would treat her. She is in constant pain, has lost a lot of weight and has had to drop out of school. Sometimes she is so bad she passes out when she tries to walk from her bed to the bathroom. I could go on and on about the horrible symptoms she has. She has lost her precious teenage years when she should be building memories. Her parent have tried everything they've heard of trying to help her. It has cost thousands and thousands of dollars. They have taken her to doctors in Missouri and are now in Kansas trying another treatment. This treatment isn't even covered by their insurance. They have taken second jobs and mortgaged their home to try to get help for their daughter. What is it going to take to get you people to wake up and recognize this disease for the monster that it is?

Richard Shelley I would love to hear comments from the IDSA...really.....

Lisa Reed Gaffney Youth and children that suffer from Lyme and coinfections...NEED THEIR QUALITY OF LIFE RESTORED!!! They have not had the chance to barely live their lives and their lives are being taken from them! CHANGE IS DESPERATELY NEEDED...and it needs to start with you heping them and their parents to help them! ITS TIME YOU STEP UP TO THE PLATE AND GIVE US WHAT WE NEED TO HELP OUR CHILDREN!

Carie Small Please do more to raise awareness. One of my best friends has been bed ridden for almost TWO YEARS because of this awful disease (the first portion without a proper diagnosis) If she didn't have it, I would not even know what Lyme WAS. That right there tells me that not enough is being done to make people aware that this is a serious serious thing. To all the Lyme patients and caregivers out there, hang in there...you all are some of the very strongest people I've seen and I'm constantly praying for a change, a cure, and more hope!

Tammy Hermary *Please admit to your faults, blunders and inaccuracy. Start to make amends by standing up for all those who are suffering and change your guidelines to reflect the truth. Remember the whole world is watching you!*

Stephanie Vandagriff My dad and I both have Lyme disease. Because of you, we've gone undiagnosed for 20 years. Our lives have been ruined and payed thousands and thousands of dollars for treatment. How many lives have to be ruined so you can make money.

Linsey Langmo Research the infected, and write new guidelines for people with chronic Lyme please!

Joni Boyd Do you know how crazy it is for a licensed and practicing medical doctor to look you in the eye and say "there is no Lyme in Texas? (substitute any state here!!)? Since when do vector borne illnesses know geographical boundaries!!! Do deer know not to leave Conneticut?? Do ticks know not to crawl out of Vermont? Do dogs, people, mosquitoes, etc. not travel out of state boundaries?? I mean, ANY intelligent person knows that diseases spread outside of geographical areas. . . How can we respect someone who believes and accepts such incredulous falsehoods??!!! Ridiculous!!! Please hear our voices!!!!!!

Allison McGill Butenschon Information and legitimate Lyme disease support/help!

Bobbyjoe Holliday Morgellons what will we do??.>>>>http://youtu.be/vB-tTt9D6U0 .
Morgellons Public Outreach
www.youtube.com
PSA

Jan Posch Hey, IDSA, don't ya think it's kind of funny that the different levels of gov't seem to hold the view of chronic Lyme? What's that, you say. Well, look at all the bills and those that are already law.

Bobbyjoe Holliday can you help the helpless????

>>>http://youtu.be/Mw2nwTPKjQ8 .

Morgellons Disease
www.youtube.com
http://allstop.com/ Morgellons Disease doesn't have to be a downhill battle. Find Hope today. -
www.allstop.com

Kayla Ann Stricklin My very best friend in the whole world has Lyme disease. Just by looking at her you can tell how much pain she is in. She has had to make so many sacrifices for this disease including school, friends, and just a normal life! It hurts my heart seeing her suffer everyday and if I could do anything to help I would. I do everything I can. I went with her and her family to her doctors appointment in Missouri. She is in Kansas right now trying to get treatment. And traveling is a very hard thing to do for her. So I am asking please PLEASE look into a cure for Lyme so my best friend can have her normal life back.

Maia Evrona I would like to see revised Lyme disease treatment guidelines that honestly examine and use well-done scientific studies rather than citing faulty studies that satisfy the conflicts of interest of the doctors creating the guidelines.

Trish Anthony Grace This year I want chronic Lyme disease recognized. And I want diagnosis based on symptoms and followed up with IGENX sensitive tests. I want assurance that primary care physicians will not ask to see the bulls eye rash before they'll treat. I WANT YOUR HELP TO HEAL US!!!!!!M

Toni Kastelic I'd like to see the IDSA take a leadership role in the treatment of what you call Post Lymes Disease. There is nothing 'Post' about it because it has never been treated or cured if you follow the CDC guidelines. CDC guidelines and 'mainstream' doctors' narrow viewpoint on treatment of Lymes reminds me of how doctors initially responded to the many symptoms of the first HIV patients.... before HIV/AIDS were understood, treatments tested, and finally treated aggressively. The first treating doctors were ostracized by their peers. DOCTERS...

Please 1) be leaders in finding treatments that are effective. Chemo is a dangerous treatment but look how many lives it has saved. Long term antibiotics is currently the only way to treat Chronic Lymes. And 2) have compassion for the Lymes patients you do see. Their lives, the lives of their friends and families are all adversely impacted by this disease. I know of one ID doctor who annouced to her peers " Send me your patients but NOT Lymes Patients."

Kathy Tagudin Cooperation with ILADS professionals to treat, cure, and publicly identify Lyme Disease for what it is...a Multiple Chronic Infectious Disease Syndrome.

Alyssa Parke-Finder More attention to chronic Lyme disease. Both treatment, insurance coverage, & public attention. My aunt suffers from chronic Lyme & I've seen how serious the disease is & how much it can change a person. This disease is still misunderstood & people need to learn more about it to educate both themselves & their families

Jessica Witty I'd like to join the crowd in saying that I'd love to see acknowledgement, support, proper information, and proper treatment for those affected with chronic Lyme disease. My hope is that 2012 is the year that changes are made by the IDSA - that doctors will be educated on what is true about chronic Lyme and that they will be able to treat patients legally and without fear - and that it is the year that my friends with chronic Lyme will regain what has been taken from them.

Robin Richman Morris I would like more in depth communication between IDSA and ILADS. I would like each member of IDSA to review case histories of people who were successfully treated for late stage tick borne diseases, that review to be with members of ILADS. For all members of IDSA to attend an ILADS conference. If this stuff isn't 'real' - then what is it? Such a large population of mostly 'type A' personalities can't all be hypochondriacs....I would hate to wish an infections disease on anyone, but sometimes first hand exposure is all it takes. Lets get something productive going this year.

Glen Searcy Care more about the public's health than the public health (and insurance) industry.

Valarie Murphy I have read through mostly all the 853 comments (as of now). I have not found a single one that is complimentary to IDSA and what it is doing to Lyme and associated disease sufferers.

Jami Mannina Hurd Lyme disease and co-infections recognized for what they are...chronic and debilitating.

Melody Moore Peckham For the heads of the ISDA to live with a Lyme patient for one week to see what we go through. Each and every day is a struggle thanks to your current guidelines. May you walk a mile in my shoes....and the shoes of countless others.

Terrill Esposito I hope with all the comments re Lymes there will be some changes. Unless one lives with it or someone they love lives with it....you really have no idea...We need some changes.

Ryan Garrett Jones Lyme's disease should be recognized.

Deborah Gilley My husband and I have Lyme. He took an early retirement from his trade to try to become self-employed because he was getting sicker, (terrible unrelenting pain, etc.not knowing the real problem). He had been to 9 doctors with different diagnosis and meds until we read an article in the paper describing the same symptoms which he had. We checked into it ourselves and was tested positive. So now since we had to live on his retirement pension to pay our mortgage, other bills, meds, we have used almost all of it. We are being treated by a LL Doc so hopefully we will be well soon and won't lose our house.TICKS BITE-- LYME SUCKS

Valarie Murphy@Bobbyjoe Holliday, I watched your Morgellans video. What better way to kill any study or awareness than to put it in the hands of an HMO (Kaiser) whose best interest is served if people ARE NOT treated. An HMO nearly killed me.
Tom Morton Just incredible and eye opening to read these posts....

Virginia Carroll I would like to see a cure for Lyme, but that means you would have to mean that chronic Lyme exists and it would take more than ten days on doxy to cure it. Good grief...because of the ignorance of IDSA doctors I have been dx'd with everything from chronic migraines, to trigeminal neuralgia, to MS. Funny....when I started treating chronic Lyme all those other symptoms went away! Thanks for helping me to lose 14 years of my life....what about 'first do no harm'?

Mary Bush IDSA should pass the baton for treating chronic infectious disease to rheumatologists, who probably have more patience and advanced medical training. What say you, IDSA?

Neil Huey Just one question for the ISDA...can that nasty STD...you know that cousin to borellia, which is also a spirochete, manifest as a chronic disease? And if so, then why not Lyme, not to mention other tick-borne disease?

Kersten Dionne Heidel More information about Lyme disease!!!!

Doug Pearl Decide whose interests you are going to serve -- those of the people or those of big money and big business. Most of America has been bought out by the latter, including IDSA. Please leave the dark side and come to the aid of the sick.

And yes, a complete overhaul of policy regarding Lyme disease. It's a disgrace and a crime.

Mary DeLisser What I'd like from you is a formal apology to Drs Jones, Murakami, Hoffmann et al.

Margaret McCormick Preto-Rodas IDSA I implore you to watch the attached video. It is a little long and VERY hard to watch, but I guarantee after you watch it your opinion about Lyme will change. Too many people are needlessly suffering - including my beautiful 16 yr old daughter. You have the power to stop this suffering. Pls pls pls do it before someone you love is stricken by Lyme and/or other tick borne illnesses.
Our Story - Life, Love, Lyme, and Faith
www.youtube.com

Steven Leninski Start helping people, investigate the men that have made the IDSA a hated untrusted Laughingstock.

Tammy Hermary Please admit to your faults, blunders and inaccuracy. Start to make amends by standing up for all those who are suffering and change your guidelines to reflect the truth. Remember the whole world is watching you!

Barbara Fletcher Rusnak Right Neil, and you can't treat that bacteria with 10 days of Doxy either....

Robin Gunn Did IDSA post this question just to taunt us? I hope that they intend to dramatically revise their Lyme guidelines to come into line with reality, biology, and science. The IDSA is in the rare position where they can both do what is right with Lyme disease and actually make more money. Why go on denying that Lyme disease is a real problem? IDSA doctors- you have a lot of patients who NEED you. BE worthy of your name. Treat Lyme disease. OR get out of the way and let other people do it. Just throw away your guidelines and let ILADS take care of us.

Mark Bentz Change the guidelines/opinions on Lyme disease/Chronic Lyme disease/Late Stage Lyme disease/reoccuring Lyme disease! Chronic Lyme disease is life changing and needs more recognition by the medical community. Lyme is one of the fastest growing epidemics happening right now.

Barbara Fletcher Rusnak I see lots of questions here, but no comments or answers. We need answers and help. Instead of making up new "Syndromes" and new brand name only drugs to treat the symptoms, we want a cure, we want our lives back. I also would like Cipro and Levequin looked into. Those drugs have made many of us way worse!

Diane Cylik Please take Lyme seriously>>> A tick bite is natures way of sticking you with a dirty needle.

Dinah Gross I want to see the guidelines changed for Lyme disease so it can be diagnosed and treated. This is a terrible disease.
Bryan Sanders I would like to see all current employees get fired and hire someone who knows what they are talking about. I don't know one person "cured" or feeling better from your guidelines. Doesn't that tell you something? Wake up!

Chelsea Woodring I'd like to go a day--just a DAY without having to talk to someone with Chronic Lyme who is in chronic, agonizing pain, or someone who is in mental anguish. I would like to go a day without someone jeering at my limp, one saying to the other, "She's got LYME. Like dogs get. Whatever." It took me about 10 years to get a diagnosis. I make money through taking surveys. There is not a day that it does not hurt to eat, to sit, to stand, to talk about what is going on with me and what has been going on with me for 10 years and what will continue to go on with me for the rest of my life. My story is one of many, as you can clearly see. What I ask for? Help. Support. RECOGNITION.

Sara E. Mason *I would like to see acknowledgement of chronic Lyme (and related) infections by the society, validation of the suffering of many, and action to address this hidden, denied, and poorly understood epidemic.*

Micheal Burke *Publically recognise Lyme Disease for the awful disease that it is.*

Bambi Albert
https://www.facebook.com/photo.php?v=340058432680545

Bryan Sanders If there is no chronic Lyme and it's so easy to cure then take all of your top board members and let them get bit by an infected tick. Then wait a few years and then tell us how helpful you and your guidelines are to the truly sick.

Bobbyjoe Holliday @ Valarie Murphy it's been killed anyway, are you kidding me the C.D.C. has been sitting on a study for Morgellons & still has done nothing, the one thing I know as a fact if the Government & the C.D.C. doesn't help to cure now over 300,000 people world wide (more will join us surely) & this is a fact!!!

Maureen Daly Realistic guidelines please. Otherwise it's not 'my society'.

Kim Brown I would like to request that IDSA review the many posts posted here in regards to the prevalence of Lyme in our society. This is not an imaginary disease. So many live with chronic invisible illnesses and it is a travesty to be treated as a "nut" or that it is "all in your head" when you truly have a medical condition that is going undiagnosed and untreated. We need to wake up and address all aspects of medical diagnoses in our society today and not limit it to the diagnoses that get all of the attention and media from hollywood supporters or political agendas. Lyme is a real condition. Thanks for listening!

June Whitehead yeah apoligize to dr murakami and others who try to help us instead of leaving us to die!!!!

Simon Dragonshadow Pearce
A) an acknowledgement Lyme Disease actually exists.
B) an apology and admission that it can take years to treat, not weeks.

C) guidelines revised, more Doctors trained to treat both Lyme and Chronic Lyme

D) less mis-diagnosis and patients treated properly first time.

That is all.

Laurel White I'd like to see Lyme disease publically recognized as the awful disease that it is. I have struggled with it for over five years now and I can't even count the amount of doctors that have told me 'I'm crazy' or 'It's all in my head'...this disease needs to be recognized by doctors.

Trish McCleary Rocognition of Chronic Lyme disease and education to physicians regarding 2 standards of care available! ILADS standard of care saved my life.

Julia Bjerre I would like to see clear treatment guidelines and approved doctors and Infectious Disease Dr.s trained to properly treat Lyme patients esp those with chronic or late stage Lyme disease.

Sara E. Mason I would like to see acknowledgement of chronic Lyme (and related) infections by the society, validation of the suffering of many, and action to address this hidden, denied, and poorly understood epidemic.

Micheal Burke Publically recognise Lyme Disease for the awful disease that it is.

Lisa Webb Jordan Well, I think it has been said. Chronic Lyme is a real disease and it is time for the physicians to get educated. My daughter has suffered for 4 years. We have been to 15 different physicians and specialists with noone being able to help her. She was left alone to suffer for years. She can't go to school or participate in sports or even get dressed in the morning without help. Last month we finally got a diagnosis of Lyme. I wish my physician knew more about this disease. Especially when my daughter's 1st Lyme test came back equivocal and showed all the symptoms but she wouldn't treat because there wasn't a bite with a ring. I wish one of you would walk in my daughter's shoes for a day. It is unfair and cruel what is being done to patients with late stage Lyme. Time to work on a cure.

Carole Stocker-Hall Please make this year the year that the medical community recognizes that Chronic Lyme Disease is a devastating disease, and it's going to get completely out of control if your guidelines aren't corrected to reflect the truth. All doctors should be Lyme Literate so that quick diagnoses can be made and treatment can be started and kept up for however long it takes, without the fear of losing their licenses. Changes need to be made NOW!!!

Lisbeth Brendle Danner I would like to see all options for treatment on the table. Right now the patients have no options and the guidelines are so strict that most doctors who follow them only look at lab results and forget the patient and taking into account symptoms. Please take a look at the success stories of people who have been treated in a different often more aggressive manor and work the those doctors who have had success getting patients well!

Judy Kargel Dwire I would like to see a change in the protocal for Lyme Disease. I also would like for the doctors that are treating Lyme with long term antibiotics to be free to do so without other doctors coming down on them. I also would like to more research on Lyme, perhaps finding a better way of testing, good antibiotics used to kill the bugs. For the Idsa to say there is a chronic Lyme and that they want to help be the solution not the problem.

Melissa Dempsey Publicly recognize that long term antibiotics help chronic Lyme in the majority of cases. Your research used for your guidelines was done by individuals with a conflict of interest. Your a political force that is cheating the public out of the treatment they need. You attack doctors who give patients the treatment that provides recovery from this horrible disease. I am a health care provider that treates my patients like I would treat my family. Its time you do the same.

Rick Gross I travel from Chicago to Washington DC to get treatment for my Lyme. Figure out how get doctors knowledgeable in diagnosing the disease. Not one of the 13 doctors I went to in Illinois had a clue what Lyme disease is or looks like.

Kaethe Mitchell My daughter tested CDC positive for Bb (Lyme). That means the CDC recognizes all the positive bands on her western blot and agrees she has Lyme disease. When I called our county health department to report it (Broome County, NY), the woman to whom I spoke said she could not report this case to the CDC because we had not done the "two-tiered" testing, ie we did not do an ELISA first and if that were positive, THEN the western blot. We skipped the ELIZA because it had proved to be worthless for my other child (negative, followed by a positive western blot years later, which we found out about doing on our own). Does it make any sense that this case is not reported as a statistic? IDSA, why?

Jacinta Cox Acknowledge and update recommendations for chronic Lyme disease...it's time for the IDSA to keep up with biofilm research in regards to Lyme disease.

Debbie Thompson I am originally from Long Island, NY, and moved to Florida in 1977. Dunedin, Florida. I heard "in your head" til I was almost dead, by doctors, for many years. I've had these infections for so long, undiagnosed, that my children were born with it. One Infectious Disease Doctor (surprisingly, an IDSA member), was the one to save my life. I thank God every day for her. She found Lyme, Rocky Mountain

Spotted Fever and Typhus, and there's probably more that I haven't been able to get tested for. That was in 2007. Without her wisdom, bravery, and compassion, I would not have lived to see 2008. I tell all my Lyme friends that not all IDSA doctors are bad eggs. I know of one real doctor in your society! You folks could learn alot from the doctors who are on the front lines, and actually treating this pandemic!

Courtney Lynn Do something better than watching people`s lives be ruined by this disease while doing nothing about it.

Iman Woods Do SOMETHING.

Kimberly Aldrup-Otto TRUTH!!!

Rafal Reinfuss What would I (as a Lyme patient) like to see from you, IDSA?
- stop denying the problem we have with chronic Lyme disease - start helping to find a solution.

Please address the simple facts:
- Borrelia infection can persist despite short treatment and frequently does so - there is plenty of scientific material proving this clearly and explaining why this happens; syphilis spirochetes persist and the severe consequences of this fact have been known for decades now! How come Borrelia spirochetes would be so much different?
- Borrelia can form biofilms and there is direct evidence of that - making Lyme a possibly chronic disease by definition
- chronic Lyme disease can now be proven DIRECTLY by culture; there will be so much more direct evidence coming soon!
- this will also directly prove the existence of seronegative Lyme disease, sending your recommended ELISA testing to the bin

IDSA, please stop ignoring substantial scientific material that has already been gathered out there and start listening to the REAL experts. REAL experts are those who CAN treat what others cannot or do not want to.

The problem of chronic Lyme disease is not going away. The problem is growing and there is no more room for denial.
It is not just America, I am writing this from Poland. People accross the globe are severely affected by your malpractice. Ladies and gentlemen, this shame is on you!

Karen Metcalf I would like you to take an unbiased, fresh look at chronic Lyme disease and associated co-infections. The symptoms are real. There are too many of us who can't afford the most effective treatments, and most of us have permanent damage due to misdiagnosis and/or limited treatment options. Please make an honest effort to analyze the real data available and help us. Please... help us.

Barbara Link-Jones I am so happy to have my daughter back. Lyme is "Real! I pray doctors will do heir research and help all patients suffering from this terrible disease.

Richard Shelley FOCUS on a cure, not a cover-up...hold your heads high and get to work, it's time for a cure

Melissa Zancanella Dunn I'd like to see the stance on Lyme Disease changed...

Nichol Hebert Acknowledge both acute and chronic Lyme disease, Update treatments for both acute and chronic Lyme disease. Educate the public and DOCTORS about both acute and chronic Lyme disease. TREAT individuals with acute or chronic Lyme disease!!!

Jenny O'Dea I would like to see the western blot bands be put back to before the dearborn committee days, no more restrictive bands, no more restrictive guidelines, Lyme disease is not a one size fits all illness & should not be treated as such! Chronic, persistent infection has been documented in animals, just because we're human doesn't mean we're all making it up! By saying something doesn't exist stifles further knowledge & expertise, especially when those who say it does exist are ridiculed, fined or lose their license. Time to make some big changes for 2012!

Rand Boyd Appropriate guidelines for treatment that address the many facets of this disease. More research into a cure for chronic Lyme disease. And an aware from doctors that it is a real and not imagined disease. For a disease that does not exist; there sure are a lot of people that are suffering from it. All of them cannot be imagining the symptons.

Mary Michael I would like Lyme disease to be addressed and the cost of testing and treatment costs recognized. It seems like treatment and testing for other diseases are covered by insurances and the prices are not out of pocket charges or outragous.

Sheri Mahood Recognize that there is a problem with the testing first of all, and that all the people who are suffering can't ALL be crazy; there really IS something wrong with these people. How about connecting with IGENEX Lab in California and discussing the tests and the results they are finding. How about connecting with ILADS with the intention of really learning something about how to treat this disease? Oh.... there are so many things you could do if you really were interested in helping those of us whose lives have been destroyed. Compassion....

Ingrid Boutilier McAdam ... for any one of IDSA members to find a conscious...I know...completely crazy thought and highly unlikely!!

Seppi Garrett We need real answers on Lyme and the co infections. To not only causes distrust and disbelief in your desire to help us.

Kimberly Aldrup-Otto It makes you look careless, uneducated, greedy, to deny 100's, 1000's, and 100’s of 1000’s of people around the World that know more than you do about a disease that has been around for over 40 years. Ridiculous to have such a disease this day and age in the United States of America and around the World be denied. You can't deny us any more, this is enough evidence to put you in your place of NEGLECT.

Lindsey Galligan I'd like to see public recognition that use of long term antibiotics and IV therapy improves the health of Lyme patients! I'm 18 years old and I've been suffering from Lyme and a coinfection since I was 13. My Lyme specialist saved my life. I want focus on a cure for this easy to contract and hard to diagnose/treat disease and its coinfections!

Tressa Pearson-Franks Braam Please change your stance on Lyme Disease. There are so many of us suffering and we need your help.

Jane Smith Lyme is silently killing and disabling many people, and it is being misdiagnosed as CF and FM. We need to increase the parameters of diagnostic criteria. People do not realize it is a spirochete, like syphilis, and has the same symptoms, and often has up to 4 co-pathogens! It will disable the immune system.

Michelle Shaffer For those of us w/ Lyme Disease which was NOT cured by Doxy, please look deeper into the disease before giving guideline which do not show the whole picture. I tested positive via the Western Blot - twice. The 2nd test showed even more bands than the 1st & was done months after taking 6 wks of Doxycycline. I took it exactly as prescribed, so this is not a case of non-compliance. Also, I had been sick for about 3 yrs before I was diagnosed. Several doctors in my area (Houston, TX) told me we do not have Lyme in this area. I ran across the symptoms & had to ASK to be tested. Doctors NEED the information to help patients, and when your guidelines give them incorrect info, how can they treat patients effectively? At this point, I've been ill for 15 yrs. Better guidelines for doctors might have prevented this & hopefully will help others in the future.

Mike Geraci More research needs to be done on Lyme Disease to come up with effective and accurate treatment guidelines. The current guidelines prove to be ineffective leaving many sick and helpless. Utilize your resources and make a difference in the medical community and help those who are in need of professional advice. More importantly give the right advice!

Nina Moore Just do the right thing!!!

Bricily Jule Kaufman Consider all of these comments a small sampling of the plight faced by countless sufferers. With that in mind, give these comments the weight they deserve. Does it mean more to you if there are those of us who WERE highly educated? Who were successful? I say were because we've watched it all be taken away by this illness. Regardless of socioeconomic status or education we have all suffered the same fate. We have all fallen from grace and none of us will ever be who we were. Everyday we look in the mirror and say remember who you were is really who you are and keep trying to get your life back.

Chronic Lyme is real and it robs us of our quality of life every minute of every day. It steals from our children, our loved ones. It is not living it is barely existing. Your dismissiveness is beyond reprehensible. What do you say to yourself when you look in that mirror? Better yet, how can you? Find me. Ask me. Like countless others, I will tell you and show you. If you knew me, you would have no choice but to admit you are wrong. And, if ever the day comes that even sees me just better, I will stand up and fight. In the meantime, it is you who are supposed to be fighting FOR US not against us. And if you can't do that, do the honorable thing...bow out, disband, take a pass and get out of the way. Either do that, or admit you are wrong and make it right.

Linda Ford Davis How can your unrealistic guidelines even begin to compare with the thousands of people suffering chronic Lyme. How can you sleep at night?

Deb Labarbera I would my life back.... the life I had before I was misdiagnosed, mistreated, dismissed, ignored and laughed at while searching for someone to treat me for chronic Lyme disease. Can you give us our lives back? If not, can you please change your guidelines so doctors are NOT afraid to treat us in fear of losing their license? I recently lost my Lyme doctor because he was treating chronic Lyme patients. Now there are thousands of his patients with no where to go. I was recently hospitalized for 2 days. The doctor who observed me told me I had fibro and needed to see a psychiatrist. He obviously never looked at my chart. My blood work showed there were many things going on in my body that neither fybro nor mental illness would cause. You have brought the fear upon doctors to treat those of us who need help to LIVE. WHY? I really do not understand. This doctor took me off my Lyme treatment and I relapsed- now back at square one and VERY sick.

Would a cancer patient be taken off their chemo? I think not. Would an AIDS patient be taken off their treatment? I think not. So WHY???? Why are you dismissing chronic Lyme disease exists. If it is because blood work does not always show a positive result for Lyme... well neither does fibro OR mental illness- yet doctors are so quick to diagnose us with things such as fibro, mental illness, CFS, Chronic Pain Syndrome, IBS, Restless Leg Syndrome, Carpal Tunnel Syndrome, etc-I do not believe those are shown up on blood tests either. Chronic Lyme disease is not only taking life as we knew it away from us but for some it is killing us. Please..... Please educate yourselves. Educate others. But EDUCATE the TRUTH about chronic Lyme disease and NOT the mis-truths to save money for insurance companies. http://www.myblindspotjourney.com/

Shelly Scott LOL I hate to point this out but u should notice the questions was NOT "what would u like to see from infectious disease society" it SAYS "from YOUR society" meaning, not asking what u think about about them LMAO!

Mike Garrone Independent studies on Chronic Lyme Disease please...

Deb Labarbera It might be too late to help me get my life back, but I hope and pray that POSITIVE changes will be made for my children, grandchildren and every one else who unfortunately gets this rapidly growing disease. Please help us. People help our children.

Alisha Meston My dog was diagnoised and treated better and faster then a human!!! How is this possible?

Jason Lipsett Ignorance and self-serving biases are making the lives of people with Lyme disease even more difficult. Not only are there thousands prevented from getting the necessary treatment but there is unfair stigma attached to though struggling with the debilitating disease and its co-infections. These are NOT desperate individuals looking for anything to blame for all their problems and these are NOT helpless individuals who are taken advantages by quack doctors and labs. These are instead people who need to get better and are sadly sometimes forced to be become their own self-advocate in order to do so. Nobody enjoys taking long-term antibiotics and supporting medication, but as we are learning more and more everyday there really is no alternative.

While some of you do acknowledge that there are people suffering, you still haven't changed your viewpoint since the very beginning when we didn't have all the research and knowledgeable doctors that thankfully treat what is Chronic Lyme Disease. There is a moral obligation for you to completely modify your guidelines so people can actually be healthy once again. This is a major problem that stems from the top. If you open your eyes it just might amaze you on what you might find.

Linda Prather Nevius Please review your policies on Lyme disease. New research suggests that spirochetes are more resistant in some people. Also better testing criteria should be developed. This disease is spreading rapidly. I live in Georgia and it is more common here than is being reported

Ginny Schmalix Please reconsider your stance on Chronic Lyme Disease. Develop realistic guidelines for treatment. Advocate for your patients. Train docs to recognize Chrinic Lyme Disease. There are many things you could do to fix your wrongs. So many people are suffering. I know you could do great things if only you'd listen.

Kathrin Lyme Ebeling While IDSA refuses to communicate with ILADS and acknowledge persistent Lyme Disease or (Neuro-) Borreliosis, billions of patients are suffering with a chronic and debilitating disease that is already epidemic. This is not only affecting Lyme disease patients in the US, but all over the world.

Angel Williams Spell i have a question....are the board of CDC and the board of IDSA ELECTED OR APPOINTED?

S.c. Sorensen Look at all of these Lyme comments! Im not saying I'm sure what the RIGHT treatment is, but you should start accepting that this is a real problem that will only get worse. Help us, please. Leave the politics behind and reexamine how you handle this terrible disease.

Reva Cotton More research and a cure for Chronic Lyme and for you to admit that it exists would be a great start!!!!!!!!!!!!!!!!

Carol L Smith I live with a person that nearly died from chronic Lyme disease and was misdiagnosed for 15 years. Support the people with chronic illnesses instead of the Doctor's that do not have a clue about this disease.

Richard Shelley We pay your salary, now get to work finding a cure already...

Dawn Giles I would like the last 16 years of my life back. Chronic Lyme exists and needs to be recognized for the destruction it causes.

Justin Tolan Please be honest about Lyme disease, its prevalence and what docs should know to treat it. Lives are being ruined and lost, and arrogance and politics seem to be the winners.

Julie 'Hamm' Hagen The existence of Lyme, chronic Lyme, a cure and education.

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Rita Ryan I would like IDSA to become a reliable resource for the dissemination of information related to Lyme Disease, and to end the apparent polarization of Lyme Disease patients and practitioners. We need IDSA to work with us, on our side, helping LD sufferers and informing the medical community of effective treatment guidelines appropriately.

Joanne Veras Bull Help everyone that needs help.. These people are suffering and nothing is helping

Brittany Wedd I went from studying Astrophysics and preparing to go to a school to get my Bachelors and then Masters degree on it, to working at a gas station. Though all the formulas and theorems are still up there, the hunger and quest for the basics still raging, it is slightly difficult to pursue a degree in ANYTHING, when you're facing $5,000 monthly prescription and doctor treatments for a disease/diseases that society wont accept. I've been without treatment now for two years because the price of my treatments were too high, the infectious diseas specialist calling my Lyme specialist a quak and telling me that Lyme is not persistant, that Neuro-Borreliosis is non-existent, and that I'm lying simply to get pain medicine, when in actuality I would just like an antibiotic other than Dioxcyline that doesn't cost me the exact price of my Kidneys.

I would just love to have one month, just ONE, of IV treatments. But instead, that is until IDSA can change their parameters on this disease and the various COINFECTIONS that come with it, I will be stuck working at a gas station barely managing to survive the hours that I work without passing out from the pain, without having a seizure on the sales floor, without forgetting every single thing, and maybe just maybe not burn my hands and arms from the lack of feeling that is ever present there. New years resolution??

Carol Graham Shekhar I would like the IDSA to reconsider their position on Lyme disease. Twenty-one days of doxy did NOT work for me with an early diagnosis and immediate treatment. My illness was confirmed by a positive Western Blot (labcorp) approximately 6-8 weeks after the onset of my symptoms. My PCP diagnosed it clinically and started doxycycline 100 mg bid within 5 days of the onset of symptoms. My symptoms began to resolve within 24 hours. At the end of the 21 days, however, I continued to run a low grade fever in the afternoons. I saw a new PCP on the 23rd day. Based on this fever,

and the epidemic of Lyme in our area, the new doc added another 90 days of the same dose of doxy. After approximately 45 days of doxy (with a two day break), I began to experience muscle weakness, fatigue, and mood swings. My PCP advised me to stay the course with the doxy. I became rapidly and progressively ill, becoming unable to drive, work, or care for myself and my 4 year old child.
I found an LLMD, who prescribed Biaxin and Rifampin (clinical diagnosis of Bartonella). Within 8 days, the mood symptoms were gone. The other symtpoms improved slowly but steadily over the course of a month based on my detailed symptom log. Seven months later, I am much improved, but still struggle with much less severe fatigue and a couple odd (but not troublesome) symptoms. THE BOTTOM LINE: If Lyme was hard to get and easy to treat, I should have been well with the 21 days of doxy. I was not. Different medications worked quickly. I am lucky. So many are so much sicker than I. Still, my experience should be enough to warrant reconsideration of the IDSA stance on Lyme.

Tracy Garrett Hughes Please look at your testing protocols for Lyme Disease! Reconsider your guidelines for treating Lyme and your belief about Chronic Lyme. I have been fighting this awful disease for too many years! I am tired of being misdiagnosed and for doctors not having the knowledge they need to combat this terrible epidemic!

Marissa Bella Cassella IDSA, I have been suffering with Lyme and several co-infections for many years. I'm only 19 years old. Please have heart and do the right thing and change your guidelines to the correct information. The arthritic pain, bone pain, spine pain, GI pain, head pain, nerve pain, cognitive pain, and neurological impairments that I am faced with each day could have been prevented if I was informed correctly about Lyme disease. I blame IDSA for not being informed correctly. I had to give up physically going to school, dance school, walking, having a social life, etc, because Lyme ended up causing paralysis in my legs. This is serious, Lyme disease is real! With the proper, long-term antibiotic therapy, and IVIG, I am now walking again, after THREE YEARS. Those three years I will never get back. I think of other kids who are younger than me who are sick with Lyme. You have taken away their lives because they cannot function with Lyme. They cannot get treatment because of your guidelines. Us children are the future, so why won't you change the guidelines? How would you feel if your child was infected with Lyme? Or your spouse? They would be bedridden.

Lyme disease is sheer torture. None of us ever thought that going outside (especially in areas in which you consider 'non endemic areas') would get bitten by an infected bug and be cursed with this illness. You can't keep refusing to believe in an illness that thousands and thousands of people are being diagnosed with. Us Lyme patients have had our lives flipped upside down. Some don't have homes or automobiles. You know why? Because they can't afford them due to paying out of pocket for Lyme literate doctors and proper treatment. Many people can't even work to earn money for treatment. You know why? Because they are crippled from Lyme. PLEASE change your guidelines. This disease almost killed me. Please start acknowledging how devastating CHRONIC Lyme disease is.

Diane Ostrander Open your eyes about Lyme Disease. Require co-infection testing for everyone diagnosed with Lyme. The Lyme and co-infections running loose in the nations blood supply is a crime. Lower the bar...so that people who still have Lyme can be retreated. Test the darn donated blood! Diagnosed in 1995. I still was one band short of being retreated for all these years. So very sick...so very unfair. Paid out of pocket for a co-infection test. I had Babesia. Why? Why did I have to suffer for so many years? How can you allow this to go on? People are dying, people are sick. Then you allow the entire blood supply in the nation to become infected with this debilitating illness? Make it stop! And because of my short treatment...it's BACK! thanks so much. Do your job to help keep us well. Open your minds and do the right thing.

Denise Longman After having researched Lyme literature since 2005, I am completely mystified by the lack of development of the Antigen tests and microscopy, particularly dark field microscopy and the new floating focus methods.

Antibodies are variable from strain to strain, from person to person and from month to month; whereas the presence of the bacteria themselves is surely a better marker of infection. Spirochetes and L-forms have been easily seen in the blood of people such as myself, after 19 years of previously undiagnosed borreliosis.

In the face of a growing pandemic, I would ask that microbiologists work together with physicians in a massive combined effort to heal us and to prevent this misery for future generations. Do not leave it to commercial ventures, but act now as guardians of your country's health, and provide leadership to all other nations, as the USA did in so many ways in the past.

Heather Lea Hyde I agree we need to have more recognition on Lyme disease.

Linda Rademakers After being told for many years it was Fibromyalgia, hormones and me making myself sick- thank God for Dr Cameron and his staff. I really dont know where I would be right now if not for him. Why can't chronic Lyme be recognized and treated. To think that I could have been well years ago, what a criminal act. Wake up and see those who are suffering!

Sally Saler-spitz Stop turning us away. We need your help! Come together with ALL OTHER organizations who really take Lyme disease seriously...make collateral contacts and find an answer...a solution to our problem...not an excuse! We are all on the same side...I hope.

Jackie Chuba Neeley I would like to see change in the protocol for Lyme disease. More research or a cure!

Susan Easton more drs with knowledge to treat this disease. Research for a cure. Easier ways for patients to get help. One Dr my son took his 2 year old son to said he should take him to a psychologist...wrong answer.

Neil Huey *Coincidentally many "newer" so-called disease states were being born or at least increasingly diagnosed; i.e., chronic fatigue, fibromyalgia, physco-somatic disorders, motor neuron disease...all at the same time tick-borne disease was dramatically increasing with frequency. Just look back at CDC statistics over the past ten years to correlate.*

Philip Grazulis acknowledge chronic Lymes. nothing is the same without your health, help us get ours back

Connie McMartin Revision (overhaul) of the current Lyme disease guidelines - allowing doctors to actually HELP us! And without risk to their livelihoods.

Andrea McLain Fennell https://www.facebook.com/photo.php?v=&fb_source=message Please see the attached clip, short and to the point. Taken from an Interview with good friends and advocates Joy and Alan Burdge.

Valerie Callen-Badillo I would like to see one of my best friends get her life back!!! To be able to walk again, to hold her son, to kiss her husband, to be able to live. There are solutions the people with Lyme are not test rats. Give them the help they need. STOP TURNING THEM AWAY!!!! Have a heart and realize these are people in pain everyday!!!! Constant pain. LYME is real, Please help them fight it!!!

Robert DeLong Please rewrite your Lyme guidelines and incorporate all scientific research and unknowns and uncertainty. Please open your minds and hearts while you do it. It's time. And there is no better time than now to.

Neil Huey I tried to connect Andrea but couldn't.

Keilih Mark Gates I would like to see the same amount of effort that is currently going into the cover up and denial of chronic Lyme disease going into the treatment and diagnosis of Lyme disease and related co-infections.

Kelly Edmonds Lyme disease can quickly take over one's life. I would like to see the IDSA work with ILADS and Lyme literate doctors in developing new diagnostic and treatment standards for Lyme disease. Lyme literate doctors need to be able to practice without fear of losing their license. There is hope, but too many people are suffering needlessly under the current standards.

Michelle Riffer Baltimore, Maryland - We need help. I don't care for an apology or admission of guilt, I need to know that you're advocating, changing guidelines and educating on the seriousness of chronic tick borne diseases and how to effectively treat. I want you to read each word of these responses and hear the stories, to see the power you have in re-evaluating and appropriately revising current protocol.

I was infected with Lyme, Erlichia, Babesia and Bartonella and experienced various intermittent multi-systemic issues (primarily neurological and GI) for a year before I was tested for Lyme (+), and treated with a 21-day course of oral Doxy. At first, my symptoms improved and I thought that was that. I'd never heard of chronic Lyme (or known about the possibility of co-infections) and when issues reappeared and new issues arose it never occurred to me that it could be the Lyme, because I'd been treated.

It's as if you'd been treated for strep throat, if you get a tickle in your throat or a fever 3 months later, it wouldn't occur to you it was the strep, you'd been TREATED for months earlier. After 5 years of off and on issues, over 25 specialists, the removal of my appendix and then my gallbladder a year later (at the age of 22) and my weight dropping to under 100 pounds, my mother finally started researching on the Internet as she was watching me slowly die. Imagine our disbelief and frustration to see literally thousands of pages on chronic Lyme disease and the controversy surrounding the proper diagnosis and treatment. After much searching I finally found a LLMD who confirmed the Lyme, and in addition found that I had 3 co-infections.

Over the past 5 years I've paid tens of thousands of dollars to get the best treatment I can afford; money that I'd rather have in my daughters' college funds. I don't do this because I'm crazy, for attention or any other reason other than I want as close to a healthy existence as possible. It tears me apart that to hold my daughters hurts because of my neurological skin sensations, and that if I didn't have video I wouldn't remember much of the precious moments that pass so quickly when they're babies, because of my brain fog. Most people don't know the extent of my illness because I don't get into it, even with most drs, since according to current standards I have something that "doesn't exist". After 10 years of this, I don't want apologies, I want to move forward - I want help. Plain and simple.

Kelly Patton Nanney comments says it all!!!!!

Ashley Rea I would like to see the recognition of Lymes disease! I want to see them not turn away patients! I want them to do research on Lymes disease and help find a cure for it!!!!

Pamela Robertson Folks let's stick together on this there are to many of us let's stand up to the corruption. I am down for whatever. IDSA answer us why can't we get treatment??????? Lord hear our prayers make someone listen to us.

Lisa Claiborne-Williams Please don't keep ignoring those of us who suffer with Lyme Disease. Lyme Bacteria is REAL and I have suffered with this horriffic illness over 7 years, my test results were verified by POSITIVE blood work and clinical diagnoses that I indeed have Borriella, Babeosis and Bartonella Spirochetes living inside my body. It is a grueling diesease and it is real. Chronic Lyme exsists even of you don't want to admit it, and reporting people who say this as "Harrassing" you on FB will NOT make Lyme go away. I'M BEGGING YOU TO HELP PEOPLE LIKE ME!!

Stephanie Vandagriff Linda- for your doctors protection, we don't post doctors names. Just refer to them as LLMD.

Tiffany Morgan I agree with many if not all of these comments! To Kaethe Mitchell above, the bad thing is that physicians are suppossed to diagnose based on clinical symptoms, not the unreliable testing, that may occasionally detect Lyme. Even if so, here in Georgia, with 2 positives and one test recommending testing in 2 weeks in which the doctor from Emory never bothered to call b/c he said there wasn't any Lyme disease in GA, and that the 2 previous test were false positives??? So no wonder it is under reported and under treated! I have seen approx. 100 doctors, and finally got a lead from an brain MRI report that indicated Lyme as being a possibility for two spots on my brain. I read info. and knew that was it, then had testing that proved so. I thought I had the answer and could start gettting better, but i have been told by several doctors they would help and did not and that they don't know much about it nor did they look in to it! I guess my life is not important enough to them. I'm sure they would think different if it were their family! I plan on traveling to Washington D.C. and paying out of pocket b/c I haven't been able to find anyone to help me! What a shame! There is no telling how many people have this disease and are not aware b/c physicians are not educated about it! Very closed minded! People should not have to suffer needlessly.

Please help in bringing light to this horrible debilitating disease! For those who don't believe chonic Lyme is real or could possible be in GA please be my guest and take the time to read the research @http://columbia-Lyme.org/research/cr_research.html

Marissa Bella Cassella Ignorance Doesn't Solve Anything

Renee Davis Lamborn Honesty, perseverance and integrity....many medical professionals are in the "world is flat syndrome" when met with diagnostic challenges. Mental Health should never be the "dumping ground" for failures to properly and accurately diagnose a patient. Many illnesses are not in a DM.....thinking outside of the box is critical.

Debbie Bossin Bailey I would love to see Lyme disease and its treatment be given the attention it deserves. I want to see my child, never seriously sick a day in her life, be given her vibrant life back, and not be bankrupt because of the cost of treatment, diagnosis, and great numbers of visits to doctors of all genres. I want her to be able to use her health insurance benefits to help make her well. Her devastating diagnosis of Lyme trickles down to the detriment of her family, which includes three very young children. I want them to get their mom back. I want my precious daughter back, and her husband wants his beautiful wife back.

Unfortuntely, it seems that greed, pure and simple, is sometimes the underlying force behind these downfalls in proper and appropriate medical care. "First do no harm" but unfortunately, lots of harm has already been done. Open your minds and possibly your hearts, and bring this to the forefront.

Tim Gallagher Come up with effective and accurate treatment guidelines for Lyme Disease.

Anne-Jarrell LoCasale IDSA< please apply the resources and the great minds of science towards better testing and treatments for Lyme. The number of people who have been harmed by this, and misdiagnosed for years, is unconscionable. Every doctor I know who has a family member stricken with this disease becomes a believer in how real and prevalent it is. As the daughter of a physician, THAT is my biggest proof. My daughter had been misdiagnosed for years, by some of the brightest specialists in the country. These doctors need greater awareness and better testing choices that include coinfections. My daughter is now unable to attend school, has dropped all sports and many other activities, and has trouble reading for more than 15 at a time. She is in constant pain. She is a talented, gifted student who has lost 3 years (and counting) to this disease. She is only 16 and would like to be a doctor someday. We need all of the minds of science to work TOGETHER on this and stop the needless debate. I am sure you would agree if it were your child. Thank you.

Julie Rand I want to see IDSA use and recommend the ILADS guidelines for diagnosing and treating tick borne diseases so that more doctors will learn how to recognize and treat them.

Neil Huey Ask your PCPs how many hours of training they received in medical school. The answers you receive will amaze you. What will it take for medical schools to incorporate significant tick-borne disease training on all available scientific body of evidence including that of ILADS. Recently a state governor has headed up a Lyme program/inquiry as 5 of his 7 kids and wife have Lyme disease. Hmmm...

Paul Patch I would like our society to simply show compassion, and kindness to each other.

Bobbyjoe Holliday Could anyone of you think about having a parasite inside your body & your Family's & the Medical system will not help. Morgellons Disease https://www.facebook.com/groups// .

Morgellons Group information page to connect people with Morglleons Disease, & find resources to get help & information

Lisa Claiborne-Williams Saying Lyme does not exsist is like saying "The World is Flat and you will sail accross the edge and fall off". It took just a handful of people to trek a voyage of discovery to indeed discover that the world is NOT flat. The person who initially discovered that the world was not flat-(Magellan, not Columbus) was told not to spread that news because they were afraid of widespread panic. Can you imagine? Let's just let everyone believe that if they venture far enought they will fall of the edge of the earth. Is what you are doing any different?

Amy Lackey Ricciuti IDSA-It is time to start listening and making a plan to work with the Lyme community. We outnumber you and we will be heard and make the changes necessary to get our treatment and get coverage for said treatment. It is just a matter of time. You cannot hide under a rock FOREVER!! Revise your guidelines for REALITY! Chronic Lyme disease exists and is epidemic.

Bobbyjoe Holliday Suffering in silence should not be an option!!

Lisa Sikes I would to see aggressive research in the area of chronic and persistent Lyme disease, it's treatment and cure. I would like a genuine communication to occur between IDSA and ILADS. I ask that the new guidelines be kept open until we really know what is going on. And that IDSA guidelines be informed by those participating in ILADS, as well as the information from patients like us. I would like to be able to access allopathic and alternative treatments. I would like to see funding for actual intensive treatment for patients who have been suffering with this for years, such as myself. I would like all treatments to be considered, because antibiotics have been a treatment, but not a cure. I am currently disabled due to Chronic Lyme disease, and I would like my life back!

Josie Bradley Dr's need to be educated and we need to be heard.

Tessa Mccall I would like the IDSA to admit there is a problem here with the people who are suffering from Chronic Lyme Disease. There are too many people suffering from the chronic form of this disease. I am to tell you that feeling like you have the flu (magnified by 20) on again off again is NOT NORMAL ACHES AND PAINS. The studies are there -- the bacteria is stealth and capable of changing its form to hide from the immune system and the antibiotics. Look at the studies done at Berkley on "Antibiotics can improve the disease but don't entirely kill the spirochetes that cause it," Appel says. "Some persist and six months or so later, play-up again, causing recurrent symptoms. This holds true for dogs and is likely the case also for humans." Nevertheless, with the combined arsenal of a vaccine and antibiotic treatments, it won't be long before Lyme disease is under control.

Kendra Cuyler IDSA members who are on the payroll of drug companies should not be allowed to draft treatment guidelines!

Jen Bruning Hafner I would like affordable component comprehensive healthcare, with not using fear to controll the masses and manipulate them into vaccines and pills that are useless and risky. The truth no more secret elite running the lives of Americans and all people no matter skin creed race religion sexual orientation nationilality or age. First of two continued on next comment -- no more lies!!!!! No more false information to make the pharmaceutical and wallstreet fatter and more corrupt.

Erin LaSpada I also would like my life back, the life I had at working full time with the world infront of me. That was my life before being stricken with late stage neurologic Lyme disease. I cldnt drive for a year beacause i couldnt remember how to get from place to place, in a town i had lived in all my life. I also had times i couldnt even speak. Because of this late diagnosis, I am on permanent disability, cannot have children, and can not work, as i once did. I have found positive things in my life to look at through it all. I found reasons to press on. Please find better testing, accurate testing and better treatment. We are people that didnt ask for this. AIDS patients get better treatment. and this is spreading faster than AIDS. Bottom line, we just want to be treated as human beings. and more accurate testing and treatment. Thank you.

Helen Villiers short and sweet......... CURE NOT KILL..............the truth will come out...

Rose Fox Johnson So, here's your chance, IDSA. Patients are coming to your Facebook page and sharing views that you invited them to post. Most of them are keeping their language clean. Will you pay any attention at all to what they say? Will you listen for the pain behind their words?

How about a revise of the IDSA guidelines, in an open process that allows all stakeholders a place in the discussion?

I'm willing to hope the New Year will bring some softening to your anti-Lyme patient stance.

Jen Bruning Hafner Recognize Lyme dies

Monica Zmuda Recognize chronic Lyme disease, I have Lyme and co infections. The neurological problems I have are endless! Walking, speech, memory, neurological tics, confusion. Please help us, I do not think it is too much to ask for, we want our health back. We want to be productive members of society. People of all ages are suffering, why??? I just can not understand a medical establishment refusing care, treatment, or diagnosis. I had been a nurse for over 15 years, now I can not work due to this disease. Constant pain! Mystery diagnosis, the answer is chronic Lyme disease.

Tessa Mccall Facebook took my message before I was finished. The study was at Cornell not Berkley. This is exactly what happens to me up and down roller coast ride that I have been on for 3 years and I really want off this ride. I cannot make plans because I never know how I am going to feel. Please stop this insanity for the people suffering. We are not asking you to find a cure although that would be nice! We are asking you stop anyone else from being infected. Used by permission of the Cornell Veterinary Medicine newsletter. Fall 1997 . "Faculty Profile on Max J. Appel". pp. 11 and 13. This article appeared when Dr. Appel became Professor Emeritus and was a tribute to his long career at Cornell.

Neil Huey Coincidentally many "newer" so-called disease states were being born or at least increasingly diagnosed; i.e., chronic fatigue, fibromyalgia, physco-somatic disorders, motor neuron disease...all at the same time tick-borne disease was dramatically increasing with frequency. Just look back at CDC statistics over the past ten years to correlate.

Kristen Wilson Ross Please stand by Lyme patients...It's REAL!!!

Teri Kjos I do not have Lyme disease, but my cousin does, and I have witnessed the suffering she has been going through for "far too many" years. This disease has ruined her life. I need to know why it is that veterinarians recognize the disease and it is treated immediately as such & cured. My daughter's dog was treated and cured of Lyme disease approximately 3 years ago. Also, I believe there is a vaccination for animals for Lyme disease. Isn't it time to find a cure for the thousands of people suffering. Obviously this isn't going to go away. It's time that these people are heard!!!!

Linda Hopkins-Hickman PART ONE
First, I apologize for any rude comments made by those frustrated with your organization. Please recognize these comments come out of the fact that your organization's stance on treatment protocols have greatly impacted their lives both medically and financially. Often times, leading to disabling conditions, bankruptcy due to the inability to get insurance to pay for the treatment that finally killed their Lyme Disease (most typically IV antibiotics after many rounds, doses and types of oral antibiotics, also many not covered by insurance), or both. Please understand their comments are from both physical and psychological pain and that the Standards of Care your organization has for Lyme Disease have greatly impacted their lives in negative ways and they do not have the words or strength to do anything other than lash out after their long battles with Lyme Disease the ultimately, for most of them, they have lost the lives they had prior to their exposure to Lyme Disease. So, please try to understand the pain behind the words and do not just dismiss them as "crazy" or "nut-jobs."

I am writing in hopes of actually encouraging further real, educated conversation and changes to the way you look at Lyme Disease and most importantly re-evaluate the current Standard of Care your organization has for Lyme Disease. While it does work for most, it does not take into account those who have atypical responses to Lyme Disease and/or those who do not respond to oral antibiotics—no matter how high the dose, no matter how long the antibiotics are taken (despite all the lovely side effects of the antibiotics), no matter how many different antibiotics are tried, Some of us do NEED to be on IV antibiotics to finally kill the LD germs and your Standards of Care make that very difficult for the physicians involved in our care and our ability to receive appropriate treatment, let alone get this appropriate treatment paid for by insurance companies.

Thankfully, for me, my Public Health Dept became involved in my care as my continuously highly positive tests were reportable to them. For me, it took 4 rounds of 4 weeks of IV antibiotics to finally get a negative test. Although 4 antibodies were still positive, it was below the 5 positive antibodies needed to be reportable to Public Health Dept. It took about 6 months to get the 4 rounds of 4 weeks of IV antibiotics since I needed to wait for test results to come back between rounds of IV antibiotics. Each time the test came back positive, the Health Dept recommended the next 4 week round of IV antibiotics. After the 4th round, when the test came back with only 4 positive antibodies (officially negative according to test standards?), it was recommended that I go back on oral antibiotics for 30 days. I did this; and the next test taken 6 weeks after completing the last oral round of antibiotics still came back w/some low antibody levels. The antibody levels had declined further, and as the side effects of the antibiotics were severe for me, and I was feeling less symptoms of the Lyme Disease—finally after treatment for 2 plus years. We chose to wait and see if the levels would continue to decline based on long-term treatment and test in a few months unless symptoms increased. Thankfully, that test was a few months ago and for the first time in 10 years my IgM antibodies were negative! However, we will continue to monitor the LD pathogens as my physician is well aware that the spirochete-shaped germs can still be hiding in my brain or other organs and reactivate the disease at anytime.

Second, I apologize in advance for any grammatical or spelling errors in my post. They do not reflect my educational status. In fact when I first became ill in Jan 2001, I was working full-time for a Local Dept of Health in the are of policy and program evaluation. In fact, I was attending JHU School of Public Health working toward my Masters in Public Health, with a Policy and Administration focus.

What do I want for your organization in 2012?

1) A better test for Lyme Disease. Also, a test that does not do a basic screen and then not move to specific antibodies testing if screening is not high enough. A more scientifically read test is needed. Test results should not be dependent upon the skill of lab technician.

Additionally, if you test positive for 2 of the germs identified as part of Lyme Disease, this should be enough to be treated. Even one should be enough. You should not have to have 5 different antibody reactions to "officially" test positive for Lyme Disease. The differences among individual's immune systems prior to exposure result in a variety of responses to infection with any of the Lyme germs.

2) A Standard of Care that calls for testing of all known tick borne diseases if someone tests positive for Lyme Disease. It is fact that ticks with Lyme Disease pathogens are likely to have other disease pathogens and many individuals treated for Lyme Disease do get appropriate care and the LD is killed, but they have other symptoms still. While I do agree there are some who have long term damage from LD and have "Post LD Syndrome," others are likely to be infected by other tick borne diseases but many Primary Care Physicians do not know to test for other possible illnesses and they remain untreated and are left to cause further damage to their patients.

Linda Hopkins-Hickman
POST TWO

3) Inclusion of IV antibiotics as treatment mode ONLY for those who do not respond to oral antibiotics after a specific time period and a specific cocktail of oral antibiotics, increased doses of oral antibiotics rather than a blanket statement that oral antibiotics are not the standard of care. There are patients who do not respond to oral antibiotics—maybe the disease was diagnosed too late, maybe they have other diseases that cause treatment to be more difficult, for whatever reason, there are patients who do not respond to oral antibiotics and do in fact need IV antibiotics to finally kill the disease. Many other diseases have a treatment model that provides first step in treatment, if that fails move to this step, then this step and finally, to the step of Iv antibiotics. Your current stance on IV antibiotics for Lyme Disease is causing undo brain and other organ damage to individuals who need IV level antibiotics. It is also tying the hands of specialists [even those outside of Infectious Disease specialists] who fear malpractice or state medical board sanctions. By specifically identifying when IV antibiotics should be used, in those rare cases, is a much better policy than excluding a treatment option that has proven to work for those who are not able to kill their LD in other ways.

4) An educational campaign directed at like audiences:
A) Physicians, both primary care and other specialists who end up seeing LD patients late in the disease as a result of neurological, rheumatological, psychiatric and other late stage LD symptoms. This should include all early and late stage symptoms of LD to put it on the radar to even consider LD as an option. [NIH made this recommendation for Celiac Disease several years ago and the number of cases of appropriately diagnosed cases had jumped since the program began, source NIH consensus conference on Celiac Disease]

B) Public Health Education Program that educates on other early symptoms of LD and the fact that a statistically significant number of individuals w/Lyme Disease never have typical "bull's eye rash", or

Jennifer Tate *Citizens of this country are dying, becoming disabled and losing everything because of Lyme Disease. Thousands and thousands of people have the same story, same symptoms ad same poor quality of life. We want to work, love our families and be contributing members of society not bed-bound and scared. We need to be taken seriously and more needs to be done. Recignizing that Chronic Lyme exists and changing the treatment guidelines would save so many lives and improve those who manage to still be here after suffering years of agony!*

have the rash in an area that it cannot be seen like the scalp. Most Americans think that Lyme Disease is a rare disease and you always get the classic bull's eye rash. They also think that you need to be a camper or hiker to be exposed. They forget that those deer who eat their landscaping plants carry these ticks and can easily leave behind and pass to you or you pet, then you. We are encroaching more and more on the natural habitat of deer and our homes are being built in their "homes." Much of the general public does not see this as a connection to Lyme Disease. Included in any General Public Health Ed Camp should be the increase in incidence of Lyme Disease and other tick borne diseases. Use of maps showing increases in incidence and spread of disease would be a very effective tool in such a campaign. It should also touch upon the fact the Lyme Disease is a collection of pathogens and not just one germ, the difficulties currently faced with current testing and the need to get re-tested if symptoms continue after a negative test as it takes time for antibodies to build to the level of detection by current tests and the need for re-testing after treatment to ensure disease was killed.

5) I would like to see more long-term research on the incidence of re-activation of Lyme Disease due to the spirochete that hid during treatment and come out again later due to whatever reason. The research should include tracking possible triggers for re-activation of disease. We know a great deal about the long term affects the spirochete-shaped syphilis. I would like to see research that uses that information and compares and contrasts it to what is currently known about the spirochete-shaped Lyme related pathogens.

6) I would like to see a voluntary database created to be used as a long-term research "watch" for those who have significant long-term damage due to whatever reason [late diagnosis, not killed when first diagnosed and treated and not re-tested until years later, co-occurring chronic illness that cause more significant disease than healthier individuals, etc.]. This database could not provide empirical research information, but it could be used to help Lyme Disease researchers be inspired to begin research into areas not currently on the radar. It could also provide a retrospective, although again not for pure empirical based research, look at common pre-disposing factors contributed to poor response to "typical treatment recommendations." Or a retrospective look at what treatments were used, how long after exposure to tick treatments began, or an infinite number of combinations of components researchers care to compare for those who respond to Lyme Disease pathogen exposure in an atypical manner. Then, if there are any patterns noticed, it could lead to new research paths to test hypotheses.

7) While I understand that most research is based on typical exposure and treatment and monetarily that is the priority. I am also keenly aware research funds are also hard to come by. But if you had the voluntary database described above, you would have some evidence of the large numbers of individuals who are permanently disabled by Lyme Disease. Additionally, you could request the number of individuals approved for SSDI applications (by year—to show increasing numbers) that list Lyme Disease as:
A) the only disabling disease
B) one of two or more disabling diseases and
C) the age of applicant. This data could then be used to show Congress the direct costs Lyme Disease incurs in just SSDI costs. Good statisticians/researchers can use that data and project additional gov't costs for Medicare for these individuals once the meet the 2 yr waiting period, the costs for Medical Assistance/Medicaid for individuals waiting for access to Medicare and a large proportion even after obtaining Medicare.

Additionally, many of these individuals cost the gov't in Food Stamps benefits, Energy Assistance benefits, Housing Assistance, Gov't Food Assistance via Local Gov't Food Banks, etc. Once these costs are projected, it will show the huge cost that the small population of Lyme Disease sufferers who end up disabled by the disease cost the government and the fact that these numbers have been increasing over time will give your organization the leverage to try to obtain gov't funding for this population. Additionally, this data and knowledge will help to gain private foundation funding as well as general individual donations to have the ability to fund research for this area of study.

Michelle Brown I would like the IDSA to start listening to private research scientists and the current doctors treating Lyme. Surely those that see it day and day out have some information to contribute. I would also like a voice. Listen to us, we are suffering!

Jen Bruning Hafner Recognize Lyme disease is not cureable in three months if ever and have the hard real truth be said about it because my dear friend and loving mother, wife, daughter and inspiration julianna king lives with Lyme disease and what the health community does and LIES about its treatments and insurance don't insurance over it is in American and in human. This "organization" disgusts me and the rest of the world that does not have your wool pulled over thirty eyes. Change the laws and bring hope back to real people fighting Lyme disease. Jewels king and her son deserve a fighting chance, do the right thing not the most profit margin. Save your souls before its to late! And I'm agnostic so help the good people who will live or die because of your poor laws and LIES. Sincerely, Jennifer Brining

Sally Saler-spitz We are victims of Lyme diseasee..and continue to get re-victimized from doctors who are forced to abide by the ISDA Lyme treatment "standards"

SubLyme Contender wow....over !!!!

Elaine Calderin Acknowledge all of us with chronic Lyme - we will not go away!

Renee Schultz We want to get well and get our life back. The life that chronic Lyme has taken from us. I want to be able to afford my treatment and not have to travel 4 hours to see a doctor that knows how to treat Lyme.

Bobbyjoe Holliday Many with morgellons Disease also have Lyme Disease.

Patsy Swinson We late stage Lyme disease patients desperately need recognition and help. The standards of diagnosis and treatment need updating to include our growing numbers. I have had it for over 55 years and been on antibiotics a number of times but still testing positive. It took 50 years just to get a diagnosis. That's about 50 years too long. Can't this terrible and growing problem be addressed?

Cathy Reilly Consider the Golden Rule...

Brandon Lawes Ignorance Doesn't Solve Anything

Todd Meese IDSA: over 1,000 comments. Do you get the idea yet? We are not going to be silent anymore.

Jennifer Tate Citizens of this country are dying, becoming disabled and losing everything because of Lyme Disease. Thousands and thousands of people have the same story, same symptoms ad same poor quality of life. We want to work, love our families and be contributing members of society not bed-bound and scared. We need to be taken seriously and more needs to be done. Recignizing that Chronic Lyme exists and changing the treatment guidelines would save so many lives and improve those who manage to still be here after suffering years of agony!

Jacqi Euler BTW... I have been diagnosed with fibro, chronic fatigue, sleep apnea, TMJ, heart palpitations, chronic kidney stones, arthritis and a host of other problems. All of which my LLMD believes could have been avoided if I would have been treated properly when I was first bit when I was 6. But since we live in Indiana no one knew about it. You see we were on vacation in Lyme CT when I got bit! So just because it "isn't in Indiana" (though it is) doesn't mean someone that lives here can't have it. People DO travel...

Sarah Solomon Please do something about chronic Lyme disease now!! Too many people are suffering for this not to be the top of "our society's" agenda.

Angela Kaye Mason We want help, respect, or even just acknowledgement for those of us who suffer with chronic Lyme disease.

Mary Shaffer Tick - borne illnesses are a Coming Plague! LYME is real! Stop ignoring the problem .... Great posts everybody!

Michelle Riffer That you don't ask a question and then disregard if the answers weren't what you wanted to hear. That you acknowledge and do something so this wasn't just an excercise for Lyme sufferers to vent.

Emily Mygatt Lee How about acknowledgment of the endless suffering of many thousands if not millions of Americans suffering from chronic Lyme disease, so they can finally get the help they so desperately need? That would be great (if overdue.)

Frances Murdaugh Kuhlbars We need a fair and honest review of the IDSA Guidelines by physicians who are actually treating Lyme patients and researchers working to find answers. A review and new guidelines that would not give insurance companies license to decide who gets treated or not. A review that would make insurance companies respect treating doctors decisions on treatment not just reviewing doctors paid by the insurance companies. Seems like a conflict of interest. There are people who have had Lyme and have recovered and are living as productive, tax paying citizens because they got the extensive treatment they needed. There is hope for people with chronic Lyme but we need the recognition of the IDSA and a cooperative effort between the IDSA and ILADS to share expertise and do what is right by all patients suffering.

Judy Chabot I would like to see Lyme disease taken more seriously. My son(age 10) had a positive Elisa and a negative western blot, so according to the CDC he didn't have Lyme. Well this was 5 years ago, and he has had Lyme the whole time. Now he is legally blind in one eye, and has numerous fevers, leg pains, psychological issues, etc, etc. This disease is suppossedly treated in 30 days. This is FALSE!! My son has been on antibiotics for over 2 years and still not completely well.The reason he is not well is because the doctors would not retest him for Lyme. Why do so many doctors ignore Lyme!!!!!! Especially when we live in CT, in a tick infested area!!

It is maddening, when all the doctors around here are ignorant to the symptoms and the testing for Lyme.Why does the CDC say the test is negative when you have 4 bands show up? This is ridiculous, especially in a young child!I am completely disgusted with all the Infectious diease doctors, pediatricans and therapists, etc, who abide by these guidelines. I can bet my life if any of them had a sick child with Lyme, they would change there thinking real fast!!!! Never mind the fact that the insurance companies won't pay for this disease, and you go broke trying to save your childs life!!

Jackie Gallagher IDSA needs to approach these illnesses like true clinicians...and really figure out exactly what is going on. We should all be on the same side trying to solve this very serious problem.

Heather Hugo Recognize Lymes disease, especially chronic Lymes. I know four people with this condition, and all have struggled terrifically to get a diagnosis and treatment. Three responded to treatment for Lymes, the fourth was given inappropriate medication because the doctor refused to consider Lymes a valid condition, and it morphed the disease into a nasty chronic affair that now has him wheelchair bound. Please help doctors prevent harming their patients.

Todd Meese *IDSA: over 1,000 comments. Do you get the idea yet? We are not going to be silent anymore.*

Kendra Cuyler I was only 26 when I was bit by something in Houston, Texas. It wasn't until 2006 - 20 YEARS later - that I tested positive for Lyme Disease by Western Blot. I had been sick all along, on antibiotics for infection after another, almost zero CD 57 count, primary immune deficiency, yet HIV negative, most homebound, barely able to get out of bed for the last 10+ years. Nearly zero quality of life. Being medically retired and disabled I can't afford to see a LLMD and pay out of pocket. I lost 1/2 my life already to undx'd-misdx'd Lyme disease and still the IDSA would deny me IV antibiotics. Because patents & profit and more important than individual patients! Right IDSA?

Becky Shelton West Please recognize late stage and chronic Lyme disease. It's a terrible, terrible disease...

Kendra Cuyler .... patents & profits ARE more important to the IDSA than patients...

Lisa Hilton AMEN to what Renee said, we dont want to travel hours to go see a dr. Not to mention Canada goes by your guidelines, which leaves them screwed too!

Beth Ghaphery Johnson I would like to see more education for our doctors so Lyme Disease could be detected and treated sooner.

Ray Friedman Please recognize chronic Lyme disease. It can happen to anyone. Having Lyme disease is a hopeless feeling because there are so many doctors out there that currently do not understand it. People are dying when with compassion, care, earlier diagnosis and recognition, many people could have been helped. It is not too late. Please help! This disease is very real!

Kimberly A. Walters I would like to know what normal, healthy people feel like. I was born with Lyme, have been ill my whole life, 5 major surgeries, 4 for my spine, and have 12 medical specialists. I have a master's degree but have been on disability for 16 years, almost died from Lyme, several co-infections and mercury and uranuim poisoning. I was physically extremely ill, but my mind was so bad, I couldn't remember who, where or even when I was anymore. My parents have spent almost $60,000 thousand dollars towards the intense treatment I've received this year to save my life. I hope that you finally aknowledge that chronic Lyme does in fact EXIST!!

Cheri Coussan This politicking with our health is ridiculous! More studies on Lyme, more support, more education for practitioners and patients. Why is this being kept in the dark?! This is 2012! It's time to get this chronic disease out of the closet and into mainstream medical practices! People are suffering. Do something, please.

Michael D Scull one word: results

Tricia Papps It is essential that the medical community recognizes the existence of a debilitating disease known as LYME DISEASE! POLITICS MUST NOT BE ALLOWED TO INFLUENCE YOU! DOCTORS TAKE AN OATH TO "DO NO HARM"! IGNORING THE PREVALENCE OF THIS ILLNESS AND DENYING APPROPRIATE TREATMENT TO SUFFERERS IS DOING ENORMOUS HARM! IT IS A VERY REAL EPIDEMIC!

Sara Salinas I am somewhat ignorant about this disease but know enough to make a comment. It is beyond me why the medical community doesn't step up to the plate about this disease. The suffering described by Caitye is heartbreaking....the doctors need to remember the oath they took when they started writing M.D. behind name!!!!!

Sue Roseman A serious look at chronic Lymes disease and it's coinfections and I do mean serious such as interviewing patients!

Phyllis Shaw Thanks to the ISDA guidelines my uncle DIED of Lyme Disease. His Texas Death Certificate states from Lyme Disease. His test was positive but his Neurologist in Houston stated there is no Lyme Disease in Texas. Upon his deathbed, another Dr finally diagnosed him with Lyme but stated he did not know how to treat Lyme. It was too late!

Dan Stapleton More and better information to the medical community about the risks, diagnosis and treatment of Lyme. I can't tell you all the horror stories I've heard of victims, not so much of Lyme itself, but victims of all the quack doctors and uninformed doctors who fail to diagnose and promptly and adequately treat Lyme. Your policies

Leah Sneed Mulcay Please dig deeper into the topic of Lyme Disease. This disease is dreadful and has greatly affected my life. I'm only 30 years old and have spent nearly 11 years going to doctors to figure out why I feel terrible everyday of my life. Once I was finally diagnosed only 8 months ago, I quickly found the only treatment to help me feel any better were the IV treatments. None of my doctor's appointments and none of my IV treatments have ever been covered by insurance. I can't work full-time due to the Lyme, and this has been a big burden financially on me and my husband. Something must change!

This disease is real & it's affecting people of all ages & wiping away their chance at a normal, productive life. Many of us aren't able to use our degrees to work & more importantly we aren't able to be the kind of friend and family member we truly want to be. Please take the time to listen to those of us who deal with this disease each day.

Terra Rohn Please recognize that Lyme disease is a chronic disease so people like my sister can get treatment and possible cured from this terrible disease. I pray you all listen to all these people begging you to do the right thing, try and imagine having these parasites living in you and not being able to get treatment.

Emma Kate Please update and educate yourselves further on chronic Lyme and tick born infections. We need better tests, and better treatment. Thank you.

Eva Eklund Oh and Sweden

Libby Matthews
http://www.youtube.com/watch?v=nvTLZuPpe

Ava Johnson
I would like to see the IDSA genuinely acknowledge the existence of and the necessity of treatment of long term (chronic) Lyme disease and co-infections. I know if members of your family were affected like my daughters have been affected, you would definitely have a different belief than you currently do. Once you or a member of your family has been diagnosed with Lyme, treated for the 28 days, and continues to be symptomatic, you enter into the medical twilight zone. So many doctors just write you off and are so quick to send you to a counselor, thinking that a little counseling will make you well. People with chronic Lyme deserve more from the IDSA. The IDSA needs to take a REAL unbiased look at this illness and the current research that surrounds it. There are TOO many people suffering and losing their lives to this illness! It robs moms, dads, sons, daughters, brothers sisters, of everything they love--robs them of their cognitive abilities, their physical abilities, their finances, friends, their lives! I'm living it, I know--

Brenda Sigel I would like you all to take the studies and crap that came from Yale and toss it all in the trash and start over. There is evidence based medicine that true Lyme literate medical doctor's have that you all have been ignoring or pretending not to see for years, all for the love of money. I've done my research and Steere is the one that coined the name "fibromyalgia" after treating people for Lyme with 28 days of antibiotics and if they didn't get well, he's the one that said they had fibromyalgia. Make the medical boards stop going after the doctor's who are actually admitting to chronic Lyme and actually trying to help patients. There is one great doctor, I know of, who quit seeing patients and who is researching. You all know his name, so call him up and work with him.

Christy Keep would love to see them hear our plea for help....we are suffering out here and need you to believe us and help us find a cure!

Michelle Lee Kim PLEASE, doctors be open minded and find a way to test for and treat chronic Lyme disease!!

Kimberley Langley i would like to see realistic Lyme disease guidelines that incorporate all relevant research. I would never have guessed that so many people could be left so ill for so long from this infection without IDSA doing some substantial and ongoing research. Your credibility is on thin ice-make it right.

Kimberly Aldrup-Otto Via Lyme Disease Association: Regarding Children

COSTS TO SOCIETY: A study in an Actuarial journal estimated a $1 billion cost to society in 1992 (case numbers are up 100%+ since then). According to a 1999 study in CDC’s journal, Emerging Infectious Diseases, an early resolved Lyme case cost $161, while a disseminated Lyme case could cost over $61,000, in dollars. The above referenced 1992 CDC school district estimated medical treatment costs for 54 total of the study children at $5.2 million, and more than one-third of families of the affected children had 3 or more members who had at some time been diagnosed with Lyme, including 40% of the mothers. A 1992 school district report from NJ districts presented to CDC and NIH officials in Washington DC by a Wall Township NJ Board of education member showed a one year rise in home instruction cost to one NJ district of 88% due to Lyme disease cases. Special education costs have certainly increased due to numbers of students with Lyme disease, improper classifications, and ignorance of effects of the disease on the students.

Carla Nitterhouse I would like to see Lyme disease and tick borne illness recognized and treated. It is deadly and destroys lives. I have struggled since 2008 with tick borne diseases in my body and there is no excuse for this. There needs to be more education, treatment, and a cure to this horrible disease.

Sheryl Reimers To find a cure for everyone who has been diagnosed with Lymes Disease.

Cheryl Monahan For the sake of our society. i would like to see Accurate Testing for Lyme & Co Infections, Proper Treatment, & to Educate our PCP's, Specialists. I have Lyme Disease & Babesia a co-infection. I lost my job because of this disabling disease. I did test positive for Lyme in July, had the whole nine yards, fever, circles etc. & was supposed to be treated for 4 weeks, but I awoke in the middle of the night with a knife stabbing pain in my Lower Left Leg, which became swollen. This happened 2 weeks after I started the doxy. I had an Ultra Sound to Out rule a Blood clot & the doxy was extended for 2 more weeks (6weeks total) I was told that I could not receive another dose of Doxy.

If I was properly treated & later properly tested I would not have to still suffer. I thought I was dying of an unknown disease after suffering for almost 3 yrs. My son told me it started with Lyme it has to be Lyme, to go online and research Lyme. My family saw what this Disease was doing to me. I could barely read or even breathe. But I did find a LLMD and I am now being treated with some progress. I am so Grateful for this doctor, I have Hope now & I am fortunate to be able to have found such a doctor. Please Educate our doctors & help save lives.

Libby Matthews After 10 years of misery the final straw was when my precious daughter came home the first week of high school saying her pencil fell out of her hand and she was losing grasping skills. The next week she was diagnosed with Epilepsy after having a seizure on 2nd base while playing varsity softball. Put your children, grandchildren in in her position.We have lost our house because the treatment guidelines are not in place. After 3 years of treatment my daughter can grasp and she hasnt had any seizures. She IS getting better. She was bitten at 6 and now she is 18. We have not traveled out of the state of Alabama.

Janice Bahura Acknowledgement that not enough is known about this CHRONIC and debilitating disease. And an apology that it took so long and so many were left to fall through the cracks.

Kyle Rider I would like to know, what makes a group of people ignore a problem that is staring them straight int the face? Lyme Disease is an epidemic and is quickly eating away at our society. Just mention Lyme disease to a group of friends outside of this small circle and see how many people know someone suffering for this horrendous disease. Your actions concerning this disease are one step below the Nazis actions. WAKE UP!

Allison Hoffmann-Caruana A correction on the validation of Chronic Lyme, Congential Lyme, Sexually transmitted Lyme and allowance of doctors to treat us as THEY DEEM NECESSARY AND PROPER, AND CORRECT THE GUIDELINES TREATMENT YOU SUMMITED TO ALL INSURANCE COMPANIES. WE DEMAND THE RIGHT TO HAVE OUR INCREDIBLE DOCTORS SAVE OUR LIVES WITHOUT CHOSING WHO IN THE FAMILY SHOULD RECIEVE TREATMENT AND WHO MUST WAIT BECAUSE WE ARE FINANCIALLY IN RUINS! I don't like to watch my children suffer the agony of Lyme because we have just enough credit and loan to try and save my life. Which thanks to my TRUE Lyme literate doctor, I have a quality of life that I didn't have 2 1/2 years ago. $40,000 dollars in travel expenses and ANTIBIOTICS -most of the strongest ones that have saved my life.

Kevin L Smith I would like to see the ultimate stakeholder "The Patient" have direct input into revising rigid and stiff Lyme Disease Guidelines that are so badly needed.

Laura Klobucher Thank God I read Burrascano's Guidelines for Lyme treatment. My husband had it this summer, and because we knew the signs, got him diagnosed. And treated successfully! If we had followed your guidelines, he would have not been diagnosed, and would have proceeded into Chronic Lyme. Two months of abx and he was fine. Please re-write your guidelines!!!!!!

George Bates *Please stop treating us like we are all crazy. Some of us have had Lyme symptoms for over 30 years. Your antiquated guidelines and policies have left us out in the cold and most doctors clueless about Lyme. We are suffering and dieing yet you fail to still seriously acknowledge us.*

You should put patients first and not trying to save money for insurance companies. Update your guidelines so that they fit in the real world.

Barb Brehm Recognize the long term impacts of ineffectively treated or incorrectly diagnosed Lyme disease. Understand the limitations of the current diagnostic testing. Appreciate the devastation untreated Lyme can do to individuals and their families. Work honestly on diagnosing and treating this hellish disease and know that the few practitioners who do treat the disease do effectively save lives and restore dignity to the sufferers.

Teri Kjos REMEMBER ISDA MEMBERS: Our Lord will have the final judgment of how you treated "your" brethren here on earth. The afterlife is "everlasting".

Vikki Salmela Admit that Chronic Lyme Disease exists, and many of us suffer or lose our lives from it. As long as you keep ignoring and denying the effects of Chronic Lyme, patients cannot get help or insured. Re-write the guidelines and take the politics out of our health care.

Nikki Coleman wow IDSA - you seem to have deleted my post. I was respectful and not rude and didn't swear (unlike some of your member Drs that have treated me). Let's see if you remove this post - I would like to see more scientific research that takes into account ALL sides of the "Lyme controversy" and not research that conveniently ignores facts that don't fit into the results you are after. Also, I'd love reliable testing for Lyme Disease - when we have that it will be MUCH easier to diagnose and treat. Please change the way that you have treated Lyme patients up to now - it is not a theoretical exercise, but real people, with real families and lives in ruin.

John E. Murnane IV I would like to see a country that represents its' intellgence, research, and responsibility and loyalty to the hypocratic oath. It would also be nice if I could have the last 3 years and $25K+ of my life back, my jeaopardized academic/professional career, and the credibility from my personal relationships back, due to my long 10-15 years of being infected with Lyme, Babesia microti, Babesia ducani, Bartonella, and whatever else might not have shown up. At least I know that (no thanks to the medical community), I was able to get several samples of a free PCR analysis of my blood where Babesia microti was consistently found. Basically, I think we all want to be validated and no longer laughed off by our doctors. It's sick to say, but that would make the pain less hurtful. We might as well have a cancer or heart condition and at least get some sympathy from it...right? P.S. My father is a retired physician who was asked to be President Clinton's physician at one point in his career and my mother's a nurse. I'm not ignorant, just informed.

Jackie Murdock I am not going to repeat what EVERYONE above said but if you read any of the posts you will get the idea. Lyme disease patients are NOT going away and one day one of your family members are going to get sick and you will truly learn what its like to live with this terrible disease.

Nicole Leyane IDSA, I'd like you to change your falsely written Lyme guidelines for treatment and testing and instead follow the guidelines of ILADS. Or you can just keep pretending Lyme doesn't exist (seriously, how do you guys sleep at night?) and let millions of people suffer while slowly dying, many not even aware of what they are infected with. What goes around comes around.

Andrea Garner Buttram I would like for you to re-live the past 3+ years of my life and then see if your "opinion" would change.

Peggi Mauney Why is it that our country considers Chronic Lyme Disease not a valid disease and will not allow doctors to treat it? I have a family member who has become very ill from the bite of a tick. He has a bad roaring in his ears that makes him dizzy and sick, tremors, muscle pains, memory problems, and a host of other serious problems.

Joanne Krasnow HELP! We need better diagnostics and better treatments to heal the thousands that suffer from tick-borne illness!!!!

Barbara Jackson If you are really reading this, please listen to us. So much more would be achieved trying to help us rather than pretend what we have isn't real. There are too many of us to ignore and it isn't getting better.

Shelly Hebert I have suffered from this disease since 1997. I have been "disabled" for the past two years after being hospitalized for pancreatitis, hepatitis and had to have my gallbladder removed. While on the hospital, they were injecting steroids & Benadryl into my IV every 4 hours for about 11 days /2 weeks for severe body rash. I have since learned that Lyme feeds off if steroids; if the doctors were aware of this fact and of my previous Lyme diagnosis, I don't think I'd be in such bad shape today.

I have a Masters Degree and I just recently had to ask my husband what part of the egg was the yolk. I now travel three hours to visit a LLMD doctor because the one that had been treating became nervous once my insurance company denied my IV treatments! I was finally starting to feel like myself but because of insurance I will not be able to get the treatment that was helping me.

SOMETHING needs to be done to educate more doctors and more people and insurance companies should not have the right to deny treatment if one of their doctors in their network recommends the treatment! PLEASE HELP US-Lyme patients that used to be contributing members of society. I can no longer teach special needs students in an urban school system or live the physical life that I used to -running marathons, swimming in the lake with my children, hiking with my family, etc. I feel that I cannot even be a mother to my children sometimes. HELP & NOW!

Bambi Albert you now have 1,077 comments all on the same subject, Imagine That!

Suzette Susan Mack I would like to see the health care practitioners who purposefully dismiss and refuse to treat patients with Lyme Disease be held responsible and accountable. They are not the only ones with educations but unfortunately many of us are bound in by insurance issues due to finances....and it's really tough to be listened to or heard. My biggest dream for the future with Lyme is prevention of it, as well as total and complete treatment of it for those who already have it.

Hans Takeda We desperately need your help to change the views and attitudes toward LYME Disease and Chronic Lyme..!

George Bates Please stop treating us like we are all crazy. Some of us have had Lyme symptoms for over 30 years. Your antiquated guidelines and policies have left us out in the cold and most doctors clueless about Lyme. We are suffering and dieing yet you fail to still seriously acknowledge us.

You should put patients first and not trying to save money for insurance companies. Update your guidelines so that they fit in the real world.

TJ Fitzgerald I'd like to see you adopt the diagnostic criteria and treatment guidelines set forth by ILADS.

Charles Seckman I would like to see that they are more open to the position of Lyme literate physicians in relation to chronic Lyme. I wish they would seriously consider changing the standard care of diagnosis and treatment in relation to Lyme. I had a false Elisa and went over two years undiagnosed and ended up in a wheel chair until finally getting to a Lyme literate physician that did a western blot that came back positive. Under the current standard if Elisa is negative primary physicians in my area will not pursue Lyme any further. Lyme is not easily cured especially when not caught early as in my case and many others.

Valerie Mains Wolfer
http://www.youtube.com/watch?v=LKaPrAXeY&feature=youtu.be

Peggi Mauney If a doctor is found who will treat Lyme Disease, he/she risks losing his/her license. Insurance refuses to pay many of the prescriptions. If you had children who got bitten by a tick, what would yoiu do? Watch as they slowly died? Go outside of the US to get treatment? I would like for the IDSA to allow treatment of the horrific disease that is taking over America. Is there a conspiracy within the medical community that denies these very ill people treatment?

Karen Kaiser McGrath It's time to admit that Chronic Lyme Disease exists, and many people are suffering from it. As long as you keep ignoring and denying the effects of Chronic Lyme, patients cannot get help or insured. Re-write the guidelines and take the politics out of our health care.

Nancy White Shea An honest discussion on Lyme disease and it's co-infections, please.

Maggie Fordley I am a mom of 4 and 5 year olds. I was bitten by a Lyme carrying tick while breastfeeding the 4 year old. After all this time instead of getting better I keep getting worse simple due to the inability to get proper treatment. Please allow me to get the treatment I need before it's too late.

Hans Takeda We desperately need your help to change the views and attitudes toward LYME Disease and Chronic Lyme..! Being a mis-diagnosed Lyme stricken person for over 18 years, I found it simple to get antibiotics for my dog than to for my own treatment. Doxycycline is one of the least expensive drugs on the market, yet we suffer through this life altering disease without your support while doctors who try become an outcast to their peers. Please hear us, have a heart and do the right thing..!

Anne Marcotty Lyme. Get it? Face up and fix it.

Caleb-Morgan Lang More education for doctors to recognize Lyme Disease symptoms, and more acceptance for the doctors that do treat Lyme.

Bobbyjoe Holliday Thank you for creating this page I feel it's invaluable, I would like to see a law enacted that every Doctor would have to log into a C.D.C. database of people with symptoms they don't understand, I feel this would help improve the lives of people with what I refer as gray Disease & Illness, why should Doctor's turn people away to suffer from something they don't understand, least this way the C.D.C. would be able to see hot spots for any unknown Disease or Illness & can act quickly to help those in need

Bonnie L Huntsinger I would like to see Lyme disease and all tick/vector borne diseases acknowledged, treated, given full weight due to the debilitating nature of these entities. My life has never been the same ...or "normal" since I was bitten by ticks canoeing the Narrows of the Harpeth River in 1989 near Nashville, TN. Babesiosis, Lyme and other coinfections have cost my family enormously and continue to take a toll. PLEASE HELP US BY LISTENING TO OUR REAL LIFE TRUE STORIES. And please apologize to Dr. Jemsek and others like him who tried to live by the medical oath to help save lives. Thank you.

Phoebe Klemz i have read that the California blood supply is contaminated by babesia. i myself donated my blood before i was diagnosed with Lyme disease and the co-infection babesia. the babesia didn't show up until i was treated 2 years for Lyme. i was not a cdc positive. by your guidelines i would have never been treated for Lyme and the babesia would not have been discovered. the ignorance is going to effect our blood supplies even further and many will be made ill by this disease unless you face the facts.

Timothy Grey REMOVE The Lyme Disease guideline panel! Rescind their membership and restore the dignity the IDSA once had. 1,000+ similar comments in hours in not a coincidence.

Andrea Garner Buttram I'd like for you to: be bitten by a tick and forget about it because there's no Lyme in GA, wake up a month later with the sudden onset of constant nausea, electrical sensations throughout your body, rashes on your hands, vomiting, pain every where, fatigue, lose control of your hands, uncontrollable muscle tremors, and migraines --- have several doctors tell you they haven't a clue but here's an antidepressant (no thanks); Then a few more months into it begin experiencing (on top of all the other) heart palpitations, anxiety attacks, paranoia, depression, floating joint pain from one area to another in an hour's time, dizzy spells. Have a few more doctors tell you Fibromyalgia just happens and you just have to learn to control it OR my favorite...it's a bad case of MONO!

Develop food allergies/sensitivities out of nowhere... Meanwhile your baby son is suddenly 2 and you cry because you wish you could be a real mother all of the time. Drop out of Grad School because you can't think, read, or remember where the car is in the parking lot. Suddenly realize a year later ALL THIS can be traced back to the tick bite a year earlier once your husband reminds you of this.

Find a doctor who cares and is compassionate --- even admits yes you have all the clinical signs of Lyme and Bartonella, but I will not prescribe abx. She did lots of good things for me, but in the end she was scared to put her license at risk and I had to move on because I had to get better. She didn't know what else to do for me. In the end, my son is now 4 and he has a mom who's been much better the past 8 months because of what I HAVE RESEARCHED AND DONE FOR MYSELF- it was do or die- I self treated for months with GREAT results. Took a break and self treated some more. I still have nagging issues but now 3 days a month are a struggle instead of 30. And in a bit, I will self treat some more because I LIVE IN THIS BODY EVERYDAY and intuitively know what makes me better. God forbid anyone in your family should suffer from Lyme- I wouldn't wish it upon my biggest enemy.

Stephanie Brown I would like to see Chronic LYME Disease recognized for the debilitating disease it is, proper testing and treatment.

Jack Vandagriff In 1984 I had a red bulls-eye rash on my left forearm and the doctor said "don't worry about it it's just an allergy". Memory and confusion issues that same year prompted an MRI that showed white dots throughout my brain and the doctor shouted at me "you're a f...ing hypochrondiac!"

I have been told six different times that I am terminal but in spite of some close calls I'm still here. I've listened to doctor after doctor say that I'm fine, it's in my head, MS, Behcet's Disease, psychological issues, the way I was raised, chronic fatigue, Haradas, my mother must have been abusive and on and on. I've had an ablation for atrial fib brought on by Lymes, enormously swollen lymph nodes surgically removed because of Lymes, vision issues, weakened immune system that has allowed my body to be attacked by melanoma, Atypical Fibroxanthoma and Squamus cell cancer.

I've had vision issues, balance issues, joint inflamation and been diagnosed with Crohn's Disease (wrong again, it's Lyme). It wasn't until two months ago that a doctor said, "Let's look for Lyme Disease." He was the first doctor over 27 years to mention Lyme and to research my history of signs of Lyme in this long journey, but all the other many doctors were content to give an incorrect diagnosis and take more than one hundred thousand dollars from me and my family - and they couldn't care less, they have a hold harmless clause for mis-diagnosis and lethargy.

But, I tell you, the worst part about this entire thing is that my three-year-old daughter was bitten the same time I was. We not only chased doctors for me, we chased doctors for her. Her life has been severly compromised because of QUACKS and indifference from the medical profession. Thank God for the courageous doctors who are treating Lyme patients and SHAME on the CDC and the mainstream medical establishment that only cares about the drug lobby!

Kaethe Mitchell This year, I would like to see IDSA recognize that many people get bitten by ticks, perhaps the tiny poppy-seed sized nymphal ticks, and they are not aware of it. My hairdresser noticed her 7 year old daughter had lost an earring. When she looked closer, she saw a nymphal tick attached near her ear. She removed it and took the tick to the doctor. It was tested and came back positive for Lyme, but the doctor unbelievably told her not to worry unless her child became sick. This did not sit well with her; she knew how horribly my children have suffered with late-stage Lyme, bartonella, and babesiosis. She called another doctor in the practice and insisted on antibiotics.

Question: She could have missed the tick had she not noticed the ear without the earring, warranting a closer look...so how many of us have been bitten by an infected tick and we did not know it? IDSA, you must know that this happens and could lead to late stage Lyme. Didn't see the tick, didn't see a rash, no diagnosis, no treatment, years of illness, doctors and specialists, lost school, sick days, crying, pain, suddenly not able to function.

Lisa Nagy Please stop ignoring us, LISTEN to us.
You have the ability to help us all. Please make a change!

Nancy Gillispie Lyme is an insidous diseaes and it has robbed my 17 year son of his childhood. There are very few Lyme Literate doctors and most people have to travel long distance to get help. Pretty much everyone in know from my support groups with Lyme have become bankrupt. This country needs more research dollars towards this disease and for the IDSA to stop making this a fiancial and politic topic..... those afflicted are desperate for you to listen and to care.

Cory Riffer What would I like to see from IDSA this year? Please recognize that there is a chronic Lyme disease and that there are treatments that should be covered by medical insurance companies. This would help hundred of thousands of people suffering AND DYING from something that is treatable. I have watched my beautiful wife persevere for years with no help for your organization. It's time TO HELP PEOPLE AND NOT INSURANCE COMPANIES!

Lisa Shogry Savage Help your members EFFECTIVELY treat their LYME DISEASE patients so that we can fully live our lives, without the unneeded debt and struggle that we face due to doctors who refuse to recognize our existence. THE TIME IS NOW!

Renee Dahlen I would like to see the IDSA take Lyme Disease and the people who suffer with it seriously with compassion and an open mind. Fight for us! We want our lives back so we can be productive and healthy active people in our society.

Jeff Slawson Medicine by means of corruption is just as irresponsible as medicine by means of superstition. Throwing salt over our shoulders is not going to cure us just as your Lyme guidelines have failed to cure us. The only real difference is that your guidelines have destroyed many of our lives (while your Lyme panel lined their pockets). Throwing salt over your shoulder only makes the floor dirty.

Bobbyjoe Holliday well, maybe professorial Health care givers are not seeing the big picture Tim with the broken Medical system we have to deal with & does little to help those in need for good Medical Service, as someone posted earlier Doctor's should be better Schooled & equipped to help everyone with a gray Disease & Illness because they have no clue as far what to do with people that suffer what they don't truly understand

Sarah Cosby Advocate for Lyme Literate doctors to be able to treat their patients in a manner customized to the patients needs and not risk losing their medical licenses, reputations, and livelihoods.

Todd Eshpeter Please help us. I have been battling Lyme and co infections for over 4 years. Yes it is chronic and we need help.

Kim Zerwas Pierre I would like to see the IDSA listen to the experienced Lyme doctors and correct the current guidlines in regards to both diagnosis and treatment! To think that in my late 30's I no longer suffer from the arthritis as I had since my early-mid twenties. To think of all the other symptoms that I suffered with quietly that are no longer a part of my life. It is incredible! Without the treatment I received from a doctor brave enough to ignore your current Lyme guidelines I don't even want to think of where I would be right now. I was finally diagnosed with Lyme when my symptoms came to include MS-like paresthesias and neurological pain. It is not fair that I should not be able to receive the same treatment at my local medical provider. PLEASE listen so others that are not so fortunate to have stumbled across the helpful advice I received can be diagnosed, treated and live more comfortable and productive lives too!!!

Harrison Case Give up on the arrogance and take a fresh look at the science.

Shaunna Marie I would like to see a Lyme disease patients treated with respect. Lyme disease is real and ignoring it WILL NOT make it go away! How would you feel if you knew you had a disease, had the proof to show it, but still had people telling you its all in your head??? Its not a pleasant feeling and has taken a toll on many people worldwide. I think its time to come clean about this disease and start making very sick people (like myself) healthy again. If you think about it, wouldnt you rather have a bunch of people working, paying taxes, contributing to society, than being sick for years and years??? Its common sense.

Michael Anderson What would I like to see from IDSA this year? Please recognize that there is an illness called chronic Lyme disease. Look how many people this disease has touched. How many more is it going to take? remember, we all aren't crazy...

Susan Campbell Chris Finkle and people who donate blood who cannot be diagnosed and treated are spreading LD to unsuspecting recipients of that blood.

Heather Haubrich-Jacobson Help us suffering with Lyme disease, it's that simple, that's all we are asking for. Tell us how the hundreds & thousands of us could possible all be wrong? Look at my profile picture. This is my husband suffering with chronic Lyme disease, my whole family is suffering because he has to pay out of pocket for almost all of his treatments. It's time to listen to us the patients, and family's. Please never forget your oath first do no harm. Your policies are harming many innocent people.

Bobbyjoe Holliday what bothers me is Doctor's are influenced by their peers & also by the politics of the company's they work for- (Hospitals) again a rethinking of political pressure, they all should have an open mind & not write people off with Disease that is not politically correct their in the business of healing not playing politics or sawed by their pairs & afraid what they think or feel, is it better to heal a person or play office politics

Kelly Smith NEW LYME DISEASE GUIDELINES.

Yours almost got me killed in high school. 20 years old and finally getting better due to treatments that you make doctors lose their licenses for even talking about. Get educated. Talk to the real people who are suffering, not the insurance companies and pharmaceutical companies who are after our money.

Hauskins Sue *Please help make sure others dont suffer any more because of this terrible disease. This is so unfair for those that can’t get diagnosed and for those of us who know they have Lyme. We need answers now!*

Adele Cyr I would've liked to have seen my sons Lyme treated before the western blot came back so his suffering could have been shortened

Deanna Bach-Talsma real, truthful, solid scientific research and subsequently change.

Valerie Cran Healing treamtents for late stage Chronic Lyme Disease!!!!!

Valerie Cran Recognition of the disabling effects of late stage Chronic Lyme Diseasee...followed by treatment that can actually help those Chronic Lyme folks get better...and stay well forever ♥

Marie Taft Turley Think about how borrelia and the syphilis spirochete are similar. When people did not get well from treatment for Syphilis back in the day, they called it "treatment failure." Note that Lyme bacteria has a much longer replication cycle than the Syphilis bacteria, therefore, it needs much more time to eradicate it. Please acknowledge treatment failure with short term antibiotics for Lyme Disease and help support those who are only trying to help sick people heal. I had full blown Lyme and have a healthy life now because of the courage and kindness of a physician who saved my life.

Ali Kirby An apology!

John E. Murnane IV I posted earlier, but after reading others' responses, I was inspired to write a follow-up. It's pseudo-sarcastic, but pseudo-realistic. If we can't get real medical help, let's just settle. Right? If you can't beat them, join them? I mean, hey, what costs the government more, Plum Island or us? The lack of acknowledgement from a massive community of managed-care and uninformed medical practitioners? Why don't we just all be allowed to go on disability and not have to work ever again. We won't be "living," but we're not "living" now anyway and we're being punished and

suffering consequences in the areas where we try to "live." If I didn't have to worry about my professors throwing my diagnosis in my face, my supervisor throwing my diagnosis in my face (which THEY have had chronic Lyme themselves, which is worse actually, b/c they can relate), and judging me after 27 years of overperformance and success academically and professionally, where the hell do we keep pulling the energy from? I'd truly like to know.
What's more expensive, because maybe we should ask for a choice? Well, no, not really, we have never been given a choice of our benefit, unless it was at the sacrifice of others, those we love and those who love us. Seriously? This *will* be my life's work. And I'm happy to say that I'm networked into some of the best LLMD and researchers in the country, so I feel confident to have a great platform to jump up from. P.S. Go Virginia for having a Lyme Disease Task Force and many thanks to all of those on the board and those who testified and to my compound pharmacist who is on it, my LLMD, and my friends at our dear friended Lyme Associations. Not IDSA, to be clear, though.

Jessica Rain I would like to see everyone involved in making Lyme disease guidelines draw straws and infect themselves with ticks. Those with the long straws can treat those with the short straws. Let's see if 30 days of antibiotics will do the trick? Surely you trust your own protocol? Easily cured right? Or maybe you'll discover it's not just in our heads.

Rhonda L Nielsen I would like to see your society acknowledge that your guidelines for treating Lyme Disease are as antiquated as the the thought that the Earth was flat...

This year, ISDA, I would like you to acknowledge that because of your antiquated way of thinking, a substantial number of Americans have lost their livelihoods, their homes and any thought of achieving the American Dream- many of us so debilitated that we cannot think beyond this moment.

Mostly, in the coming year, I would like to see ISDA, my society, work for ME and countless others on treatment that would potentially give us back some quality of life. You owe us much, much more!

Hauskins Sue Please help make sure others dont suffer any more because of this terrible disease. This is so unfair for those that can’t get diagnosed and for those of us who know they have Lyme. We need answers now!

Meredith Lodge I had "ideopathic arthritis of the knee" in 1995 while living in CT. I was diagnosed in 2009. That’s ove 15 years to find Lyme. In those 15 years, the money spent on endless specialists, mris, and X-rays could have been prevented by a reliable test. I ask that you research and produce or back an already existing reliable test.

If you add up all the needless amounts of money people could have saved if insurance covered Lyme, or if they were diagnosed early, or had reliable accessible testing, how much that could benefit our economy. If you are trying to protect us, people who did not intentionally put ticks on themselves, could you please this year find people with resolved Late stage Lyme syndrome or whatever Your Wording is, and find out how they got better. Maybe you could study them? This is a disease that causes bankruptcies, ends marriages, and breaks aparts families.

Most importantly, however, I would like you to treat Lyme sufferers with respect, and not treat them like a PUBLIC HEALTH THREAT (your words.) Instead, find a way to stop us from declining health and stop our healthcare providers from turning their backs on us because of your words.

Randy Garvin LYMERS and Lyme families: please if you can make sure to print these posts out. For some reason I feel there going to "lose" these posts and messages or maybe there FB page went down so unable to get any posts? Serious. It could happen. Our fight today and the one we will continue until there post is taken down would be for nothing. I can see directors saying "let's just tell everyone we don't really check our messages. Just used for marketing and giving out information. If we don't have copies of all these posts were screwed!!!

Charlie Knower I would like to see an honest and open discussion about Lyme Disease. I also would like to see a response from IDSA to all of these Facebook posts.

Valerie Mains Wolfer Pennsylvania State Rep Dick Hess help push the Lyme bill HB 272 .
http://www.youtube.com/watch?v=tgCqBrTU&sns=fb

Terry Lipinski listen to the people with Lyme, we are the ones who went through many nightmares trying to get diagnosed and treated for this.

Paulette Meier Please join with ILADS in a more thorough understanding of Lyme Disease and other tick borne infections. The ILADS doctors I have seen know WAY more than the infectious disease doctors available to us because they have been working directly with patients and have been willing to be out their on the front lines of this battle, treating each case differently, as need be. I was one of the fortunate ones who sought out a proper clinical diagnosis within weeks of the tick bite. Unfortunately, even with my successful effort to get my local internist to prescribe 4 weeks of doxicycline, all the symptoms came back.

Six years later, although much better, I am still in a daily struggle to function. I've had to travel over 600 miles to find a doctor who would treat me, and have had to spend thousands of dollars in supplements and pharmaceuticals to get as far as I've gotten. Your organization has caused more suffering than you'll ever know, because you are hiding much evidence that Lyme and other tick borne bacteria are incredibly resilient and incredibly difficult to treat. Your denial of the truth of tick borne illness- diagnosis and treatment- seems, frankly, criminal -- for all the deaths and suffering it's caused and continues to cause. Please hear us!

Kenneth Poindexter An honest review of the Lyme treatment guidelines taking into account research as well as the undenyable suffering of s many patients. At a minimum, acknowlegement that persistent Lyme disease can exist just like almost every other infection can. Perhaps some support for those that are suffering can receive the care they need. So many are being denied coverage based upon the existing flawed guidelines.

Stacey Mathias Kreme Honesty about Lyme Disease and Co-Infections please.

Kathryn Richards I foreclosed on my house this year to pay for medicine that your guidelines say I do not need. Me and five children all have late stage Lyme disease. I had to leave the state to get tested doctors are so afraid to even test. My free clinic would have loved to help me but cannot due to your guidelines so instead we have sold and lost everything to buy medicine and you know what! after one year, we are starting to get better. Long term antibiotics do help. Our doctors should not have to face persecution for following their oaths.

Cindy Steggall ***Bye*** *I would like doctors to have the education to be able to detect, diagnose, test and treat for Lyme legally. Not to be afraid to diagnose Lyme: that they might lose their md license. I'd like for doctors to be knowlegabke enough about Lyme to make a diagnoses, and not treat Lyme patients like hypochondriacs. One doc told me that I would (in the future) test positive for HIV. He was an infectious disease doc. I have Lyme. Uggg*

Linda J. Lane *Its ABUSE.*

Tracy Hans I'd love to know if there are IDSA doctors reading this page. Some I've encountered didn't even know there's a controversy surrounding these infectious tick borne illnesses! I went to two IDSA guidelines authors initially, and was told that there'd be a 15% chance of my spontaneously getting better (no treatment. And that no treatment was warranted (I had a positive spinal tap). So I waited. And got worse. Sad, that this is still happening.

Melissa Powell Thun I would like to see Lyme Disease properly diagnosed and treatment provided immediately without having to fight an insurance company to get the help so desperately needed. I would like the IDSA to help patients who have been misdiagnosed and left with untreated Lyme disease - patients who now suffer from extreme unrelenting pain with no relief in sight. THIS MUST BE ADDRESSED AND FIXED!

Christopher Montes Please face the reality that Lyme disease can be chronic in a percentage of cases, has multi-systemic manifestations including neuro-psychiatric and cognitive presentations, and requires heavy duty, long term, antibiotics as well as other possible treatments such as hyperbaric oxygen. Please realize that the IDSA is not the medical end-all when it comes to diagnostic and treatment guidelines. Please look at all the studies and date that are worldwide. Examine some of these patients who have posted here and give them a respectful medical evaluation weighing both medical tests and clinical presentations. Look back at why you became physicians and what you learned in medical school about having an open mind, knowing that every person has a different immune system, strains of disease are different, and manifestations of the disease are myriad.

When you have done these things, give me a call (I'm in the book here in Connecticut - the epicenter of the disease) and I'll tell you my story of months and months of misdiagnosis by nine different doctors before one doctor got it right (Lyme, Babesiosis, and Ehrlichiosis) and saved my life. Then look at my treatment, taking 8 years to finally get to a point of normalcy...then relapsing after another years. I'm not one of those who wants to be sick...I didn't make up the symptoms I have experienced, nor did I make up the positive tests and cultures I have had even after "adequate treatment". I'm a psychologist...a trained professional, affected and afflicted by Lyme disease. So please IDSA...when you ask what we want from your organization, take a hard look at what I , and so many others, have written. Thank you.

Audrey Amir Despite the combination of outrage and desperation from the Lyme community which undermines its credibility, there is something to be said about the various legitimately questionable medical practices and conclusions the IDSA has reached about chronic Lyme. There may not be enough studies done to satisfy the medical community, and that should no be dismissed, but the overwhelming anecdotal evidence of patients making medical progress once treated with antibiotics and various herbals for Lymes disease should not be overlooked. It should spur interest and further research.

Please do not loose sight of your roots and remember that once, common medical practice was to bleed individuals for a fever, treat a variety of ailments with Mercury, and to perform Lobotomies to solve mental health issues. What was once touted as "the truth and the way things are done" is not always so. Medicine is called an art and a practice for a reason. Operating on faith that you care for the good of the people and want to uphold the Hippocratic Oath, I urge you not to do harm by refusing to listen and explore the possibilities.

Jill Russell My wish is for IDSA to recognize the work of hundreds of Lyme specialist MDs and researchers on the "other side" ie ILADS supporters, as valuable and worthy of consideration. Do not dismiss the dedicated scientists and doctors who are taking Tick Borne Illness seriously and pushing research. Collaborate, with respect and common goal of HELPING US. Open minds please.

Heidi Healy My entire family of five have Lyme and coinfections Babesia Bartonella and Mycoplasma. I have dealt with the disease for 10 plus years. I have proof through stomach biopsies and PCR tests that Lyme is chronic especially when it becomes nuerological. My dream is for some leader in the IDSA to come forth recognize this and tell main stream medical America. The outdated IDSA guidelines need to be revised. Too many people are falling through the cracks with undiagnosed Lyme. Treatment needs to be tailored to the patient and a couple of weeks of doxycycline for the average patient isn't going to help them much if they have had the disease for a while and also have the coinfections on top of it.

The IDSA needs to truly recognize the seriousness of not just Lyme but the Babesia, Bartonella and Mycoplasma. If I didn't get the appropriate treatment for my children they would probably be in average classes on ADHD meds and have anxiety issues. Today my kids, though they still have it, thrive in school, are great in sports and one is even classified as gifted. It has taken me years and hundreds of thousands of dollars to get them well. Why can't the IDSA see what Lyme is doing to our society and how the medical community is turning their back on it. Please someone in IDSA get your head on straight and recognize this epidemic. I am in PA where our state is ranked number one in cases reported yet most medical docs sweep Lyme away and look at you with five heads if you even mention Babesia!!!

Carl Tuttle The online petition against the IDSA member's Lyme disease study has gathered 129 signatures from across the US, Canada, Germany, UK, Ireland, Belgium, France, and the Netherlands. Please take a moment to read why people are signing this petition.

There are now seven states which have passed legislation to protect clinicians who treat late stage Lyme with long term antibiotics (CT, RI, MA, MN, NY, NH, and TX) and there are support groups in nearly every state with nineteen in Pennsylvania alone.
If the IDSA and CDC got it right with their "one size fits all" treatment approach for all stages of Lyme disease and faulty two tier test algorithm why then do we have this much legislation involving Lyme disease?
Petition site:

http://www.change.org/petitions/subjective-symptoms-after-treatment-of-Lyme-disease

Carl Tuttle Hudson, NH
Website:
http://home.comcast.net/~runagain/site/?%Fhome%F

Daniel Keough a BAN on antibiotic use on healthy animals--used solely for the slight increase in profit margin, they are the vast majority of antibiotics used in the United States. On healthy farm animals! This is crazy and the farm factory model dependent on these drugs needs to end.

Daniel Keough Preventing antibiotic resistance and promoting public health is more important than an industrial agricultural company getting a few more pennies per animal.

Angela Hoock Yikes... all of these people suffering can't be wrong. Please do more to help them. My heart and prayers go out to all of you who are dealing with this ♥

Jayme Roche Kulesz It would really be helpful if you could just keep open minds when it comes to the treatment of Lyme disease. There are so many of us and our children who have suffered so terribly because of the inflexibility of the "guidelines." Many of us are on the verge of bankruptcy. Why not spend some time talking to us? We would really like to sit down with you and have an actual conversation about the effects of this infection. Thanks for listening.

Brenda Sigel WESTERN BLOTS WITH ALL THE BANDS COUNTED!!!!

Linda J. Lane Its ABUSE.

Traci Leister Linstrom Chronic Lyme disease is a fact that needs to be recognized. Its recognition from you would enable many suffering from this awful disease to come to quick accurate diagnoses.

Lisa Mannetti Wagner attention given to chronic Lyme disease. please help those who are suffering without the help of insurance.

Karla Lehtonen The Infectious Diseases Society of America claims that they care about Lyme patients. DON'T BELIEVE THEM!!! On Wednesday, I went to a talk by an Infectious Disease Specialist entitled "Chronic Lyme Disease." The speaker was scheduled to speak with doctors in the board room of the largest teaching hospitals in our area. The first slide of his talk was titled "What do you do when a patient asks you to treat him for a disease that he does not have?" The entire rest of the talk was designed to give physicians ammunition so that they can avoid treating patients with chronic Lyme disease. Over and over again in his presentation, the speaker distorted the research on Lyme disease, while denigrating the scientists and physicians with differing viewpoints. One member of the audience asked him, why his slides used such inflammatory language. His reply was that he didn't believe in long-term antibiotic use, because it wasn't safe.

In his confession, I believe that he revealed the true agenda of the Infectious Disease Society of America. It's not about the quality of life for patients with chronic Lyme disease; it is a misguided effort to curb long-term antibiotic treatments. It also reflects the inability of the physicians in power at the IDSA to impartially and critically analyze the data, and to realize that the studies supporting the early simplistic model of this complex bacteria and its accompanying co-infections are flawed.

Lorinda Massing Koczur With Lyme disease becoming more epidemic that AIDS I think it's time that the guidelines for us are changed. My 18 year old daughter who is a National Honor Society student now is struggling because of memory issues, becoming dyslexic from Lyme, suffers physical symptoms daily that have kept her from being a "normal" teenager. I was originally diagnosed with "a shingle" 8 years ago. Now I suffer from many of the same symptoms such as memory issue, neurological issues, and the list goes on. IDSA needs to educate physicians and the public and change the guidelines. It's sad when our Primary Care Physicians don't know what's wrong with us and just lump us into a "category" that either means we are hypochondriacs, crazy or have chronic fatigue etc. It's time to join the 21st Century IDSA!!!!

Lynn Olson-Tuma What I would like from the IDSA this year is a review of the Lyme Disease treatment guidelines and for Chronic/Late-Stage Lyme Disease to be recognized as a real disease so that us people who are suffering can get the help we need to get better. As it is now, so many of us have to pay out of pocket to see a Lyme-literate doctor because LLMDs won't take insurance for fear of losing their license to practice medicine. For someone who is sick & unable to work, it is almost impossible to come up with that kind of money. Also, when someone is sick & unable to work, trying to get Social Security Disability should be a viable option but with Lyme, it is not recognized as a disease that can lead to being disabled & unable to work because of the IDSA's unwillingness to see that Chronic/Late-Stage Lyme Disease is a real disease that is destroying people and their livelihoods.

I'll say just a little bit about me & my story. Before I got sick, I was a makeup artist working in TV & film. It was a job I loved, it was my dream job. Now, I can't do my dream job anymore. In fact, I can't do much of anything anymore. I have a beautiful 3 year old son who has been robbed of having his mommy be well and able to play with him. I have a wonderful husband who has had to become the primary caregiver to our son as well as my caregiver. He has had to do everything for us & I hate it but this is my reality.

I want to be well again. I want my life back. So, IDSA, please revise your guidelines so that this can happen for me & my family as well as everyone else who is suffering from this curse of a disease!

Cindy Steggall Bye I would like doctors to have the education to be able to detect, diagnose, test and treat for Lyme legally. Not to be afraid to diagnose Lyme: that they might lose their md license. I'd like for doctors to be knowlegabke enough about Lyme to make a diagnoses, and not treat Lyme patients like hypochondriacs. One doc told me that I would (in the future) test positive for HIV. He was an infectious disease doc. I have Lyme. uggg

Randy Ceaglske Approval of broad PCR testing for bacterial pathogens from FDA. Remember why NIAID is in Hamilton Montana ---- that was a place to learn to treat ---not test treat to patent. You ruined a perfectly good continent due to oversight of endemic disease.

Jennifer L. James I would like Lyme disease to be taken seriously as well as all it's awful co-infections. I would like Lyme patients to be treated with dignity and respect and for insurance companies and doctors to HELP them instead of denying them. I want one of my very best friends to get her life back after being bedridden for 18 months!! I want her to be able to play with her son!! I want her to be able to get out of her bedroom, out of her house! I want her to be able to enjoy life instead of struggling through each and every day just to stay alive.

Jason Orloff
Dear IDSA member,
Better treatment

Kate Bellando Acknowledgement that your current Lyme testing & treatment guidelines are both ineffective & inhumane. I was diagnosed & treated for Lyme with 2 weeks of amoxicillin in 1984, at age 4. Since then, I've been labeled with the countless autonomic, arthritic, & psychiatric conditions associated with late stage Lyme until finally testing CDC positive via western blot last summer & getting long term care. After 6 months of treatment with multiple antibiotics, (none of which was covered by insurance of course), I'm finally having days where I can tend to my own basic needs again. I'm no longer able to work, and at 32, I have no idea what feeling "well" feels. Don't let this illness continue to destroy lives.

Fran Davide I would like to see GP's, ID and Nerologists INFORMED enough to test for and recognize Lyme Disease so that it can be treated from the onset. Rather than leaving patients undiagnosed and left to fend for themselves and forced to research and discover that Lyme Disease exists and is a serious illness. My 15 yr. old daughter was perfectly healthy until until July 2007. In August 2007 she went to a cottage and in Sept. she started to have neurological symptoms as her brain was affected. She had 3 hospital admissions and a multitude of tests and Lyme was never considered as a serious option for her diagnosis. It took me as a parent 10 months and it made a lot of sense to recognize the possibility of Lyme and by then my daughter was seriously ill. Finally, a Lyme literate doctor not in the mainstream, had her tested in the US and her tests for Lyme were positive. In Canada they are still not recognized. We travelled to Germany, Italy and the US for treatments.

Today I still struggle with Doctors who admit that they don't know enough about Lyme disease. Today, my daughter is totally incapacitated. She no longer talks, she cant stand up and she does not walk.She needs full time care. It has been a grueling 4 years. A mother's worst nightmare. The saddest and most frustrating fact is that she remains undiagnosed and doctors don't know how to help her leaving her in palliative care. We need more research, more awareness and more open mindedness from Doctors to look at this seriously and find ways to help all these people that have been affected. Worst of all, if my daughter were to pass on right now she would be labelled as cause unknown. As a mother, I want to know what happened to my beautiful healthy daughter and know the cause. I would like to see a fully funded research centre that could bring some light to this horrible disease and help people like myself to find answers to the mystery of having lost a fully functioning daughter. www.chiaradavide.com

Muriel Lynch I am the parent of a daughter with chronic Lyme disease. She was diagnosed with MS, ("BUT you've got something else going on here,too") at a highly respected medical clinic. MS treatment made her much worse. For 13 yrs with dozens of specialists puzzeled by symptoms, a MS diagnosis and 3 neg. Elisa tests in a few mos. we were encouraged to further look into Lyme. The result of the IgeneX test was Positive Lyme and 6 Co infections. The financial and emotional piece to all of this has resulted in her loss of a terrific job, loss of our home...paying for medical not covered by insurance, most importantly an uncertain future for a 31 yr old who has much to offer. I could go on an on, but I trust that these words and those ahead of me are getting the point across. WE NEED YOUR HELP AND UNDERSTANDING.

Bev Feldman I would like you to train your doctors to recognize Lyme. We took our very ill daughter to 20+ doctors, including IDSA members, and not one of them recognized LD. The delay to diagnosis (9 months) allowed it to go into her brain. It did not have to be that way. It really didn't.

Keith Poullos IDSA not only affects USA patients. Iit has all but totally shut down any hope of Canadian healthcare giving us Lyme disease patients any help. Because of your ridiculous stance on Lyme disease we in Canada cannot obtain testing or treatment here. For some unknown reason our medical institutions and government want to follow your extremely biased views on Lyme disease. All I can say to you is to quit with the false statements and lies and maybe everyone can get some much needed relief!

Brian Dutze Please focus on Lyme Disease and related infectious disease research. That would be most helpful to many thousands, and in all likelihood, millions of Americans.

Eva Eklund If not any of you (IDSA) click this link and read about Chiara. The reality she and her family live. Then i dont know about human anymore. Again. This could be you next. Please do something. You CAN. Be the ones who make a change. You will shine!

Juliana Vidich REALISTIC and EFFECTIVE treatment guidelines for Lyme disease and other TBD's that are based on the experience of real doctors who have for years been treating people who have TBDs.

Eva Eklund see the link on Fran Davides comment ♥

Brenda Sigel I'm thinking since your policy on Lyme sucks you should just turn all tick borne diseases over to ILADS.

Melanie Sullivan I wish you would stop turning your head when people are truely affected by Lyme disease...please consider this.

Amy Clare My entire family, 3 generations, all have Lyme disease!! Why doesn't the IDSA explain that one to me??? Congenital Lyme disease is real!!!

Michelle Morris I would like to see other treatment options for Lyme, and to let you stop being ignorant to Lyme disease before it gets more out of hand in our society.

Becky Moore Please consider doing whatever it takes to help the many, many people who are losing years of their lives due to misdiagnosis, lack of proper medical treatment, and the emotional distress of not being taken seriously. My daughter would like to have her best friend back!

Darlena King Two generations in my family are sick....this will all come back to bite you in the butt someday.....

Shelly McCormick Scheyder Please review your guidelines for testing and treatment. I had a classic case of Lyme and was treated for 2 weeks of Doxy. Now 37 doctors later I am still very sick and cannot afford treatment. I have been told I have ALS and various other very serious conditions only to find after years it was Lyme. It is in my heart and my brain. I was in a job I loved as a nd grade teacher for for 25 years with a Masters in Special Education, but due to Chronic Lyme I am unable to teach and raise my three children. It saddens me to see so many productive members of society lost due to dated standards. Please listen and respond to our message of hope and desperation. We are trusting you have heard the message by now. People... Real people are suffering. Praying for answers and action. Thank you!

Chris Morbelli-Urbanowski I would like to stop being treated like a criminal for having a disease I contracted while walking in the woods.

Roz Thomas Change the guidelines so that Lyme disease can be adequately diagnosed and treated. Stop pretending this disease does not exist.

Chris Morbelli-Urbanowski I would like to see doctors treat their patients to the best of their ability without fear of losing their licenses.
Courtney Lynn I would like a repsonse for all of us who are pleading with you,pouring our hearts out,and voicing the truth!

Denise Weaver I would like the individuals on this Board to do the right thing and admit that Chronic Lyme Disease is indeed a growing and terribly harmful disease. Do the right thing.

Sylviane Schwarz Dear IDSA, It is with great sorrow that I have learned today that we lost a great member of our community in Humboldt County California. Lyme disease interrupted his career and ultimately his life. I have had the pleasure to meet Steve several times during his struggle with Lyme disease and I only can shade tears right now. So much for your easily diagnosed easily cured motto… Revising you position in regards to Lyme disease and other tick-borne diseases will not come a moment too soon… Below is the obituaries of today announcement of Steve Shearer http://www.legacy.com/obituaries/times-standard/obituary.aspx?n=steve-philip-shears&pid=

Denise Weaver This disease is rapidly spreading.Eventually it will harm someone you love...your daughter...your wife...you....your elderly father.....do it for the sake of saving them

Jill V. Easton I was bitten by a tick in an upscale residential neighborhood. A cat that lived in the same neighborhood fell ill the same time period I did - with the same symptoms. The cat's owner told me that the veterinarian immediately tested the cat for Lyme Disease and put the cat on antibiotics. I was misdiagnosed with MS, then other diseases, then dismissed by the head of Infectious Diseases at a huge medical center. The cat recovered and went on to live a healthy life. I went on to develop late stage Lyme Disease, multiple coinfections, and lose everything in my life - physically, financially, relationships, career and more. Had I just gone to a vet rather than physicians who follow your guidelines, I would have had a better chance of the proper diagnosis and treatment.

Jason McInnis Better testing and treatment for Lyme disease!

Denise Weaver I would like you to realize that from the time you hopefully read this until you even table the statements made here, at least one of us here will have died......

Lisa Hilton IDSA~ Noone can change what happened in the past or why we are became sick. But it's in your hands to change the future! Please, we need research and a real cure. Look at your kids tonight and go to bed thinking about if it was one of them or your wife or your husband that was sick.

Sarah Myers Please do the right thing for those of us suffering with chronic Lyme disease.

Han-Yu Loo I would like IDSA to publicly and broadly admit chronic Lyme disease is real and work together with other organizations for a cure and good insurance coverage for those who suffer from the disease. There are too many people needlessly suffering.

Denise Weaver Recognize that children cannot attend school, cannot play football and without your help.....these children will become sicker...unable to attend college,dependent on the welfare of our United States. many of them will marry ...and pass the disease onto their spouse. Many will deliver babies who will already be born with Lymes.This is already happening at epidemic rate.

Denise Weaver I would like you to deny that President Bush had Lyme disease while in office.

Jennifer Schierholt Please make every effort to educate doctors about Lyme and encourage them to treat for Lyme when someone with Lyme symptoms walks into their office. My husband had textbook symptoms - EM rash, fever, joint swelling, pain - but was told he couldn't possibly have Lyme "because we don't have Lyme in Southern California". 2 years and three dermatologists, three allergists, two immunologists, two rheumatologists, two cardiologists, two hematologists, two opthomologists, a neurologist, an oncologist, two gastronterologists, and an infectous disease specialist later ... he has yet to receive any treatment for Lyme. Now he has swelling in his heart, brain, spinal cord and eyes, facial numbness, cognitive imparement, bone pain, and vision and hearing loss. This didn't have to happen. It should not have happened.

Paisley Wilson I'd like to see up to date training of ID specialists in the area of chronic/late stage/disseminated Lyme disease. I'm not interested in blaming anyone for past errors or misjudgements, but I am interested in seeing people whose lives have been devastated by this disease get access to informed treatment. Although the neurological and psychological effects of the disease cause Lyme sufferers almost as many problems as the physiological ones, and we may not be able to express what we are going through articulately, we can't all have manufactured the same set of rather odd symptoms with such eery consistency. This is a serious and complex disease for several reasons:
1) the various borrelia strains are difficult to isolate/test for
2) there are usually multiple co-infections
3) biofilms help hide the bacteria from the immune system
4) the spirochetes are able to corkscrew their way into just about every organ/tissue in the body
5) the symptoms wax/wane and are transitory
6) the disease mimics many others, so is difficult to pin down in a differential diagnosis and
7) neither GP's nor ID specialists have received enough training in this area to confidently make a clinical diagnosis. Sure, they are starting to do a better job of catching the acute cases - and I thank you for that! But, let's really look at the people who slipped through the cracks before anybody really understood the havoc un- or misdiagnosed Lyme could cause. What a physician called a 'spider bite' (classic EM rash, but hindsight is 20/20) robbed me of over a decade of my life. I've spent my life's savings trying to find relief. Please work with health care providers in other countries to come up with an effective plan to help Lyme sufferers become productive members of society again. Thank you for your time and for asking this very important question.

Michele Noble *I would like to see Chronic Lyme disease recognised as an official disease. I have a dear relative who suffers greatly and has multiple standard lab tests to enforce her claim, yet loses her battle every year due to the "black hole" in Medicare because Chronic Lyme is not an official disease.*

Tom Morton Just incredible and eye opening to read these posts....

Shari Ridosh Dexter I can see 'not jumping to conclusions' but IDSA has had decades to come to terms with LYME Disease and it's debilitating effects when misdiagnosed. I'm praying for you people!

Kaiti Nagel Leave your ignorance re borreliosis behind...awaken to the reality of this epidemic.

Julie Engle I'd like each person on the IDSA board to consider, "WHAT IF YOU"RE WRONG?" What are the consequences to the lives of millions of people if your stance on Chronic Lyme and your IDSA Lyme Treatment Guidelines are ABSOLUTELY WRONG (as is becoming abundantly clear from the evidence)? What is the cost to society, the US government, and all tax-paying citizens? What is the human toll? The untold suffering of millions? Pursuing such an agenda, to no one's benefit except insurance and pharmaceutical companies, and those in their pockets (yourselves?), is not just MALPRACTICE, it's simply INHUMANE. If you can't do the right thing, step aside and let someonewith a conscience lead the way in 2012.

Patti Towe Ellison Change the guidelines so that Lyme disease can be quickly diagnosed to ensure less morbidity in the future.

Marybeth Ward I would like you to work towards a cure for Lyme Disease. I would like you to stop making it impossible to get medical insurance coverage for the treatments that we need to get back to really living. I would love some validation. There should be nothing hush hush or shameful about having a disease. I am a young mom of three beautiful kids and i have already missed out on too many wonderful moments because of Lyme Disease.

Joe Devenney Develop safe and effective guidelines and treatments for Lyme Disease. Create better prevention opportunities including a new viable vaccine. Don't try to control the disease but rather conquer it.

Sharon Gallagher I would like you to take notice of Lyme it is real and your present guidelines almost killed me because of co infections . It seems to me I have learned more about this disease then you care to look at. To take down peoples comments because you dont like what they have to say is wrong. I have decided that we will post all docs that follow your guidelines because you refuse to look further into treatment or the so called patterns on the bacterias itself. I almost died because your IDSA guidelines that the Doctor followed wanted me to wait to see a dermatologist. To 4-6 week appt. I had a blood infection. I got a call from another doctor on a Saturday nite 2 days after seeing your Dr. Gross I had a staph infection Dr gross stated was a skin disorder. He needs to go back to school. I will be an activist and will never shut up on this till you take notice. We do know what goes on. By the way I work with the public and have been more help to them in awareness then you have done in a lifetime.

It is my goal To Make the Doctors know who follow your guidelines public so the people who need help do not go to them.

Anne Sarbanis More research on a cure for Lyme Disease...

Sharon Gallagher If my post is removed for expressing an opinion it will only hurt you more. Help the people and always remember the oath you took to be a doctor.

Sharon Hawkes Thank you to the IDSA web manager for allowing this thread to air public concerns. On the property where I once lived, 4 people were independently confirmed to have Lyme. I was CDC positive by Quest labs, treated according to the IDSA guidelines, and am left with permanent damage. One person had an early infection, and is presumably well. Another person is permanently disabled. Still another, with late-stage symptoms, CDC positive through a hospital lab, was treated long-term with oral antibiotic in combination and is now well.

Clearly, there is more going on here than people "who never had Lyme to begin with" having only "the aches and pains of daily living." Patients are having subjective AND objective symptoms in the long term, and though there are risks to long term antibiotic use, if carefully monitored, the potential benefits outweigh the risks of undertreatment.

Matthew Tyler There is little to say, that can be respectful in a situation that has been the source of so much disrespect. I have been denied treatment, misled and misdiagnosed - how can I voice these events in a "respectful" way? Especially when so many who have tried have been scoffed at and intentionally dismissed?

And now friends who have voiced valid concerns to YOUR question have been blocked from this thread, upon grounds of what? -Speaking up to a question.

Don't ask the question if you don't want the answer. And please, I am pleading with you - hear the answers!

Sharon Gallagher Not sure your friend in late stage is cured. They may have got it to lie dormant.
Darlena King When you or one in your family has chronic, deadly Lyme Disease, maybe you will understand.

Katie Houman Please understand that chronic Lyme is real. Unfortuney, people are suffering endlessly, because of the inability for the IDSA to actually take the time to actually listen to those who are suffering from such debilitating effects of chronic Lyme as well as co infections.

Chris Iantosca Campbell I want the truth out. I want the guidelines to be changes so that tests/meds/doctors visits/treatments will be *covered by insurance.* I want my life back as well as my kids and my disabled husband. ALL infected! I want to be recognized.

Bonni Rooney IDSA, you posted the question, "what would I like to see in our society in the coming year?" My fervent hope is that someone within your organization actually takes the time to read each and every one of these posts and then ask YOURSELF (the members of IDSA) the question, "What can we do to help these people?" We already know what the IDSA's stance has been towards Chronic Lyme Disease - It's time for a change. Please, Please ask YOURSELF - Why are all these people still sick? And what can we do to help them?

Michele Noble I would like to see Chronic Lyme disease recognised as an official disease. I have a dear relative who suffers greatly and has multiple standard lab tests to enforce her claim, yet loses her battle every year due to the "black hole" in Medicare because Chronic Lyme is not an official disease.

Lisa Corbeil-Hollingsworth Stop hurting Lyme Disease patients and the doctors who treat us. If you don't want to help find a cure for Chronic Lyme, just get out of the way! You're killing us!

Carolin Raleigh Buttrick I would like to see a cure for Lyme disease and all of the co-infections that exist.

Christian Hornung Stop lying! There is Chronic Lyme Disease! There are many Co-infections! Listen to ILADS! Thank you.

Sharon Fingleton Allow doctors to diagnose and treat Lyme per their experience and knowledge, not per guidelines that have no basis in truth. Prevent doctors with financial or other interests in Lyme meds/treatments from being on the board dictating Lyme treatment guidelines.

Susan Campbell Chris Finkle
http://www.wickedlocal.com/northattleborough/news/opinions/x/McCleary-State-faces-a-Lyme-crisis#axzzigIwoWc

Susan Campbell Chris Finkle
http://gonzagalawreview.org////unprecedented-antitrust-investigation-into-the-Lyme-disease-treatment-guidelines-development-process/

Ana Christine Stop denying Lyme patients appropriate treatment! Stop denying chronic Lyme and its severity! Stop with-hunting Lyme-doctors! Revise your guidelines, train doctors - and do what the first task of doctors should be: Fighting the disease - not the victims of Lyme-disease. Stand up, IDSA, for the sick and suffering!

Dolores Claesson To add to this list is Yersinia which is showing up in Europe and Dengue fever which has shown up in a Lyme patient in NJ and Pseudomonas areuginosa which has also shown up in a Lyme patient in NJ. Do you really think 14 days of doxycycline will eradicate all these pathogens ? Research out of Germany has also shown that each Borrelia is susceptible to different antibiotics. Amoxycillin may be the choice for one and doxy for another but we can not test for different Borrelia at conventional labs. Really this ignoring of tick borne pathogens has got to stop. Fungi are most likely part of the problem as well.

Lymies...I would get all these tests...Western Blot for Borrelia, also test for Borrelia hermsii, and Babesia duncani and microti and Quest can test for duncani, Bartonella henselae and quintana, Brucella, Tularemia, Coxiella burnetti or Q fever, many rickettsias ie Rocky Mountain Spotted Fever, Typhus, Ehrlichia, Anaplasma phagocytophilum, EBV, CMV, all Coxsackie viruses, and now Powassan virus and its cousin Deer Tick Virus, HSV 1 and 2, HHV -1-8 if available. Parvovirus B - 19 papillomaviruses, Toxoplasmosis, Chlamydias and Mycoplasmas and get genetic tests for hypercoagulation like Mthfr and Factor V leiden, and test all your IgG subclasses 1-4, and CD57 and C3a and C4a and CBS mutations and HPU/KPU and mold testing since so many of us have issues with mold. ECP or eoisonophil cationic protein seems to suggest to docs that you have babesia. Also transfer growth factor b-1 and Beta Strep. High CD57 counts may be associated with Beta Strep.

Heavy metals have a part in this and we are low in Secosteroid D or vitamin D and some are low in Potassium and others iron. Many are deficient in all amino acids. Our hormones are a mess and the whole HPA Hypothalmic pituitary axis is the problem. We can have probs with our adrenals and thryoid...we do not convert T4 to T3 and in my case I have high reverse T3 or rT3. We are quite low in testosterone as well. Check out every hormone in your body, amino acids and vitamins and minerals. There are over 100 viruses we can get from a tick and also many parasites. The labs that insurance covers can't find a parasite when we can see it under the microscope. Quest at Nichols Institute in Valencia California can culture samples and might even be able to distinguish Brucella suis from melitensis or arbortus. We also need an MRI of our brain with and without contrast. Many lymies are showing up with pituitary adenomas and pheomchromocytomas. Make sure that you do not have these.

I have spent years trying to figure out what is in us and so far this is what I have seen. Unfortunately when your physician may take years to order all the necessary tests. Make sure you get tested sooner rather than later. One more thing .....you may get tested for Brucella today and two years from now may show up IgM positive. The immune system is overwhelmed with all these pathogens.

Tore Nicolai Fjelldal
How virus from the herpes familiy can become part of the human DNA in white blodcells and cause cronic illnesses as CFS an FM. If leaky gut can be measured by IgG-reactions to food, and if there is a viral component in the leaking from the blood to the spinal fluid in CFS and Alzheimer.

Jose-Luis Cruz One of my friend has been dealing with this for years, doctors gave her many different diagnosis and most would just dismiss her as all being in her head, but the truth of the mater is this is no guide lines on how to treat Lyme disease until is to late. Lets make this happen!!!

Dolores Claesson I guess this might be a tutorial for IDSA docs ?

Dolores Claesson Please don't delete this post for it is trying to help Lyme patients. Also both in Europe and America hunters have tapeworms, nematodes and flukes and the deer nematode when injected into a moose makes the moose move in a dizzying fashion and die.....

Annee Elliot Bottom line: 2 weeks of Doxy does not work. REVIEW AND REVISE YOUR GUIDELINES. What's needed is aggressive treatment. WAKE UP.

Ruth Myers It is time to look at the reality of chronic Lyme disease which does exist in spite of what insurance companies and IDSA want to believe. I hope you never have to watch someone you love go through what my daughter and husband are enduring. I watched the amazing improvement that took place in my husband during his 5 weeks of IV antibiotic treatment and am now watching with horror the deterioration that is taking place since treatment was stopped. But IDSA and the CDC say he is cured.......

Susan Brake
We need to be asking for more research, better testing including coinfections, and better education for physicians.

Cindy Waters Durden Change your guidelines. Establish better testing with updated information from this century not based on

Cindy Waters Durden 1980's work. Sorry hit send too soon. Chronic Lyme does exist. Quit ignoring it

Cindy Waters Durden Chronic Lyme does exist

David Day A realistic approach to openly promoting Lyme and the well being of patients, no matter what the course of treatment is, would be a welcomed change for 2012!

Catherine Fox Two weeks of doxy did not work. After needless delays with doctors following your guidelines who would not treat me, I found one who would and am in a battle now to get my life back. I've met so many others who are suffering. Please support treatment for chronic Lyme so everyone has a chance.

Ethan Comeau im a kid so it may not matter but my mom, dad and little sister have Lyme disease. I have appointment to test it for me in 1 month my hair falls out and i get tick bites in sports a lot so i am scared i will be sick like them. my mom is so sad she cries a lot now she didn't cry before she got sick. my dad has to stop the car to walk around from numb feelings in his hands shakes his hands all day and is in pain so much. mom has to lay in bed a lot when its bad and she worries every time we walk outside scared we will get a bite. we have two big boxes of vitamins she takes cups for her and my dad everyday they are so full i cant believe how many pills then drinks stuff that looks like yellow paint. my 4 year old sister take so many drops nasty one i tried once and bottles of pink medicine she hates one of them and mom has to bribe her to take it. she hates most that my sister is sick. i just want my parents and sister to be ok again they need a cure its been so many years and they are still sick. my grandma comes by all the time and she just says im worried about you to my mom she doesn't sleep worrying about her and she is older i hope she is ok to

Rob Cotter There is a scientific process that is not taking place here when it comes to Lyme. The IDSA can't determine weak protocol and then close their eyes to millions of sufferers. In an equitable society, the IDSA would be recognized as complicit in the prolonged suffering and demise of millions of people' lives. The IDSA has failed in their mission and continues to do so unabated.

Jodi Ireland better treatment for chronically ill Lyme patients

Kaethe Mitchell To Ethan Comeau above, it matters! You are a brave kid and thank you so much for posting your story here. You are describing better than we grownups have been able what our families endure and live with every day. You are not alone, Ethan! We also have "yellow paint" (Mepron) at our house as well as tons of pills. Your mom, dad, and sister will get better. It must be hard to see them sick, but they are on their way to health. Don't be afraid.

Christie Ley What would be wonderful is if the IDSA would treat people with Lyme disease as individuals and allow doctors to treat them as needed. For far too long they have been left out in the cold due to restrictions on treatment. Lyme disease is running rampant where I live, with both dogs and humans being infected. I hope that proper treatment and eradication of the disease can be found.

Cynthia Morris Thank you for asking! Please, please revisit the Lyme guidelines, this time keeping in mind the reality of patient experience. (I'd be glad to outline my reality for you! Hint: the Lyme didn't go away after a month of antibiotics.) And ignore peer reviewed articles that insist on a bulls-eye rash and confirming blood test before allowing patients to be including in the study…because those patients who were lucky enough to be treated immediately upon infection usually aren't the ones with the recurring problems! It's the rest of us you have to study before you can confirm or deny persistent Lyme. And all those peer-reviewed studies that you base your opinions on don't take us—arguably the majority of Lyme cases—into consideration at all. (cynthia@netmorris.com)

Jenny Guzdek "Don't talk bad about our docs." - IDSA. So we should spare their feelings when they do nothing to spare our pain? Spare our pain. Recognize Lyme; in return we'll spare your feelings, it's give and take.

Jenny Guzdek Why are they deleting posts? They don't want the world to know the truth. The behavior or deleting proves this.

Monday Mercer Lyme causes chronic intracellular infections that do not show up on standard lab tests. These bacteria lower the immune system causing multiple systemic disorders. They hide from the immune system making them extremely difficult to kill. Once Lyme and coinfections have compromised/disabled the immune system, latent viruses and other bacteria that are normally suppressed (such as HHV6, CMV, mycoplasma, etc.) come to the surface and thrive causing all sorts of problems, leaving the body open to all sorts of other opportunistic infections and the person with a lowered immune function.

Chronic or late stage Lyme disease is extremely serious and can be deadly. It is not easy to test, treat, or cure. The IDSA needs to develop much better lab tests, to educate the medical profession, to have treatment guidelines that enable drs. to treat with appropriate antibiotics, supplements, and/or natural antibiotics until the person completely recovers and has their life back. The IDSA needs to admit that Lyme is easy to catch but is an extremely complicated illness and is very difficult and time consuming to treat successfully. This illness is spreading faster than AIDs but we're still in the dark ages--we need educated doctors, adequate testing, and successful treatment ... AND insurance coverage for the folks with such a devastating disease!

Debra Grasley Dolores Claesson, do you mean Yrsinia pestis as newly-emerging?

Marie Starkweather Acknowledgment that Chronic Lyme exists and awareness! We have listened to your lies for too long!

Kathleen Dickson We'd like you to turn yourselves in to the FBI/USDOJ for the healthcare FRAUD that ruined discovery in every major disease for the last 15 years:
http://www.actionLyme.org/
Expand Preview

Debra Grasley So, will IDSA refund all of the money my insurance company paid out for my "treatment" so far, since my doctors were forced to follow your guidelines?

Kathleen Dickson When IDSA is either sued or prosecuted for this Lyme and LYMErix fraud, they'll say it all took place under the ALDF.com organization.

Kathleen Dickson Mort Zuckerman, the AIG Greenbergs, Philip Morris, etc.

Kathleen Dickson
http://www.actionLyme.org/ALDF_BOARD.htm

Kathleen Dickson It was McSweegan's gang who committed the crime. Durland Fish and his buddies at AIG, Mort Zuckerman etc.

Kathleen Dickson I'd say, to IDSA, we don't need you for anything. We got the science.
http://www.actionLyme.org/
Expand Preview

Karin Herrick Harriss I would like you to change your view on Lyme disease and accept that are some cures! I would like you to listen to the people who have had thier lives changed. My husband was dying from this disease, and he is an active duty soldier. I do not think he will ever regain his health to 100%, but he is alive and doing well now! And still on active duty by the skin of his teeth.

Wendy Fitzgerald Faneuff Lyme is neither "hard to catch" nor "easy to cure"! You've got it backwards. In endemic areas (which basically means almost all of the US) Lyme and it's co-infections are easy to catch. With the lack of training and support for the local pediatricians and general physicians it certainly is not "easy to cure" because they mis-diagnosed it for my kids for YEARS! My kids were told they had everything from Chronic Fatigue to "it's all in your head!" Well, it is in his head, literally!

Ruth Thomas It's CRIMINAL the way your physicians ignore Lyme! I have lost years of my life due to ignorance of the IGenix positive test - 4 months of antibiotics years later, and I'm back to being myself.

Tom Robey I would like to see the IDSA open eyes, ears and minds to the reality that Lyme disease is a serious health threat. I'm sure I cannot say much more than the 1,000+ have already said, but I will have my voice heard anyway. There is too much black and white in this issue, the IDSA leaning so hard one way, and chronic Lyme believers leaning hard the other way. No one is helped when the extremes are held on to so tightly. The only solution is to work in the grey, TOGETHER! ILADS and Lyme advocacy groups have expressed their absolute willingness to work WITH the IDSA and help all those that are suffering so terribly. It's time to listen to the multitudes, and consider that you just might have got this one wrong. We are here with our hand extended, ready to cooperate and collaborate, and do what is necessary to bring Lyme and it's co-infections in to check. Thank you for listening.

Kathleen Dickson *For the last 15 years all IDSA/ALDF have ever said is Lyme does not cause a disease.*

Jerry Leonard *As a result of the use of treatment guidelines to deny treatment, America's most egregious example of medical malpractice through treatment-denial is now an everyday reality, conducted on a grand scale, and run with the complicity of the CDC and other public agencies, which are exploiting the public instead of protecting them. I have referred to this as the institutionalization of the Tuskegee Experiment.*

Ron Crowley An acknowledgement that chronic Lyme disease exists would be a good start!

Jane Harper echoing CHRONIC LYME DISEASE being recognized properly! I have been suffering for months and no diagnosis although I know that is what I have - and I cannot find a doctor to help me--or who takes insurance!

Melinda Wimm Wolff Foster I would like to see our society place greater value on humanity over monetary gain. I would like to see us work together to create affordable healthcare for all, to allow each person freedom and choice in their own treatment and choice of physician. I would like to see physicians have the freedom and ability to choose treatments based on individual plans, not federally mandated guidelines. I would like to see greater value on real health by focusing on the root causes of disease rather than the symptoms. I would like to see America value the natural vs the artificial/immitation/chemically modified. Maybe if all these things were valued more, we would irradicate disease.

Donna MacPherson Lugar Forget Lyme disease and just refer to Vector Borne Illnesses and ensure that diagnosis is clinical! There isn't any blood work that would confirm all the various associated co-infections anyway (unless you want to pay thousands of dollars for every individual test)! Make sure ALL Doctors know ALL the symptoms of ALL the possible vector borne illnesses so that they can be individually treated! Make sure that EVERYONE realizes that it is not that rare and that there are not just small pockets of endemic areas! It is almost everywhere! Even in your own backyard!

Kathleen Dickson Ron- Here are all IDSA's reports which say Lyme is a permanent brain infection:
http://www.actionLyme.org/BRAIN_PERMANENT.htm
Expand Preview

Kathleen Dickson They obviously all know treatment fails since they are the authors of all those 20+ reports.

Tonya Dahlgren I was bit 7 yrs ago, Northern California, have a great set of drs. I wasn't actually diagnosed til Jan 2011. I've now got chronic Lyme. I did 10 months of antibiotics w no help. I am dying every day. I'd rather die now @34 then deal w this disease for the next 10+ years! I puke everything I eat. I've gained 40lbs in 6 months. I hate this LIFE! GET A CURE....THERE IS FOR AIDS

Kathleen Dickson Be careful, everyone posting here. This is likely IDSA laying bait to say someone is making a threat against them, or else to use later to say we're all nuts.

Kathleen Dickson Answer: "What was OspA?" "If you're such experts on infectious diseases, what was OspA?" IDSA can't answer without self-indicting.

Tim Lodge I would like the IDSA to acknowledge LYME DISEASE as an ACTUAL disease so the tens of thousand of people suffering in this country could get actual treatment and medications covered by insurance.

Toni Elise Romanelli Acknowledge Lyme as a Disease. And SHARE THE CURE YOU ALREADY HAVE. Because it is there. Stop making virus's for warfare. Start making a difference.

Laurie Nusbaum Miller To re-visit the area of Chronic Lyme Disease. I am living proof that this IS a chronic disease, and should be treated as such. I am taking medicine for Fibromyalgia, Depression, Anxiety, Joint Pain, High Blood Pressure, Restless Leg Syndrome, Insomnia, and GERD. 2 years ago I was healthy, with a full-time job and active in the community. Now it hurts just to get out of bed. How is it possible that I can have all those conditions, AFTER being diagnosed with Lyme Disease? I haven't been able to work in almost 2 years. And I am STILL NOT even getting the necessary antibiotics that may actually CURE the problem. It makes me angry...on top of everything else. STOP THE LIES!!

Sandi Bohle Acknowledgement of Lyme Disease as a disease and better treatment for those of us with chronic Lyme. Your guidelines do not acknowledge us & for the most part, my mainmstream doctors refuse to believe even tho the tests have proven it. I have had to go to a doctor out of network to get any help. LYME IS AN ACTUAL DISEASE!!

Denise Presnell-Weidner I would like Infectious Disease Clinics to quit turning away patients with Chronic Lyme, just because the CDC and IDSA think people should expect to experience 6 months of symptoms. Those 6 months just seal in the disease and makes it last for 20 years. Treatment has to be immediate and continual until the bugs are dead.

Allysia Moran I gave Lyme disease And possible co-infections to my children during pregnancy. We all have positive western blot tests. We all went miss diagnosed for over 2-3 years. I went misdiagnosed. My you vested starting showing symptoms as a baby but no one could figure out what was wrong with him, diagnosis of failure to thrive, no energy , sick kid, had surgery for tubes twice before 2 years old including adenoids and tonsils, more allergies then the specialist has ever seen for such a young kid, GI problem. six months after oral antibiotics almost all his symptoms are gone. We need better testing, open to be open minded about treating Lyme till people are no longer sick. It took IV antibiotics for me to start to improve with long term antibiotics. I'm getting my life back but had to advocate fir myself and kids. Went to many specialists for my self no diagnose. One doctor told me he could make one up cause he could. Finally I found a doctor who knows more about tick born illness and getting my life back. Of all those specialist I saw not one checked me or my kids for tick born illness. When everything was ruled out you think they would check into this due to my history no. They rather make something up then deal with the problem. I would like to see change Lyme looked at like any other illness as a clinical diagnosis their is more then one test to check for Lyme, better education for all our doctors. To except long term therapy especially when it was not our fault we where miss diagnosed. Change needs to come thousands have been through this and agree.patients should have some decision in their health care with any other illness they do.

Alicia Marie Campanella The insensitive tests through labCorps and Quest left me undiagnosed for a year. Finally after going to a reputable lab, I tested positive on almost every band, and I am still battling chronic (Thats right CHRONIC) late stage neuro Lyme borreliosis. We need people on the panel who are NOT influenced or paid by insurance companies. We need the ones doing the most intensive research, the ones on the FRONT LINES working with real Lyme patients every day to call the shots. IDSA, your guidelines are flawed, based on speculation and ignorance. And because of you we have an epidemic that is not being acknowledged or treated. YOUR GUIDELINES ARE THIRD WORLD and there are THOUSANDS of people who are about to rise up, hold signs, march to congress and make the whole world aware of your crooked motives. The gig is up IDSA. TIME FOR A CHANGE!

Gary Engelman Take a look at my Lyme Disease National Registry. Recently launched, but these are the numbers the CDC doesn't have and trust me when I tell you 10's of thousands more will show on this site. Http://ldnr.us

Gary Engelman http://ldnr.us/ Lyme Disease National Registry

Paula Davis Accurate testing for Lyme disease, Independent treatment studied on Lyme disease aimed at a cure not just treatment. MEDICINE IS INTENDED TO HEAL....NOT JUST MAKE MONEY STREAMS FOR DOCTORS HOSPITALS AND LABS! Medicine is humanitarian social support NOT a multi- billion dollar enterprise business......get back to the the foundations of medicine and the Hippocratic Oath.

Kathleen Dickson IDSA needs to be prosecuted to "make an example out of them." The BMJ just recommended this. I wonder if this is IDSA pretending to be healthcare representatives of some sort, all of a sudden.

Kathleen Dickson For the last 15 years all IDSA/ALDF have ever said is Lyme does not cause a disease.

Kathleen Dickson That would be the reason IDSA is now unfunded. They don't need money to research an infection that doesn't cause any illness.

Jack Vandagriff Jack Vandagriff Interesting how my posts are continually removed because they criticize the inept doctors that allowed my daughter and I to run through the medical profession for 28 painful, debilitating years seeking help, getting none, having incorrect diagnoses while all the while the incompetent doctors took well over one hundred thousand dollars for doing absolutely nothing of value. IDSA needs to recognize the disease and seek a true diagnostic test and cure. I venture to say there are some of us chronic Lyme patients who, sadly, wish that your young daughter or grandchild get Lyme so you can see the suffering and finally be motivated to help instead of hindering.

Janis C. Sommers The ISDA splits hairs between acute Lyme infection and Chronic Symptomatic Responses from the initial Lyme infection /and multiple tick bites. This is how the ISDA is keeping down the diagnostic process and this is what fuels the outrage from those of whose lives have been so altered by the initial experience of finding the tick on our bodies and so very often, getting late diagnoses. We are in a game of semantics riding on an emotional rollercoaster. I think the ISDA is more mature than to let this game continue. When we say chronic Lyme, we might mean chronic symptoms from co-infections - which may be treatable if so much time was not spent on the denial of treatment, and/or permanent physiological damage from long term undiagnosed untreated bite infection. I've had health problems from both conditions.

Be nicer to us, don't deny our realities, and we may actually be able to listen to what you have to say without our rage. I've treated myself with diet, detox cleanses, vitamins and acupuncture and every alternative and complementary practice that I thought would help me for 16 years, and continue to do this, but 3 years ago, I smart ARNP read my blood work and determined I had a co-infection (Babesiosis). I was treated and I am 85% stronger and more functional. So simple. And for all the other years I was so sick, my Lyme tests did not show 'enough' bars for the CDC to allow for a Lyme diagnosis. But, they also never allowed for anything else to be going on so insurance would not have covered the thousands of dollars of antibiotic treatments even if I had agreed to them 16 years ago. Please open your eyes and stop being so narrow.

Leslie Boswell Farrell Answers for my children as to why they are so sick and are not getting better. Why they can not think, play sports, date, drive, finish school, go to prom, go to football games, have fun, plan for college and have a life. Answers for my husband and I how we are ever going to pay for all our bills and ever consider a what ever life for our children if we are not around. What is our future? What plans do you have for future research in Lyme Disease and co-infections when you do not even mention it at your conventions? Why is this disease being ignored? And if you think there is no such thing as Chronic Lyme Disease then What the Heck is it?

Neil Huey Standing ovation to you Janis as you have hit the nail on the head. So much relies on semantics in this rather complicated discussion! Instead of using the word Lyme consider using tick-borne disease and that may foster more effective dialogue.

Laurie Rosenbloom Gottlieb Better treatment guidelines for vector borne infections in addition to better testing . I would also like recommendations to test for several vector borne infections in addition to Borrelia.

Wanda Cooley The Truth is going to win and you are not going to be on the winning side. I have great compassion for what this Team will suffer AFTER.

Michelle Murphy At least listen with an open mind to ILADS and hear what we are all saying. Read all the research not just the ones that validate your own opinion.

Edeline Hubregtse I've had symptoms since I was 4 years old. I'm 51 now. Life is hell. And all the 70 doctors I have seen in my life misdiagnosed it. They still won't treat me. So I'm treating myself. And my familie. Getting better step by step. Studied herbs, mushrooms, psychologie , nutrition, environment and now micro-biologie. I'm working on it and getting closer. Please pray for me and all the other scientists , to find a definite answer to these horrendous patogenes.

Christine Keller Lyme Folks, Please post your state/country of origin. We need the IDSA to recognize this as a national outcry for justice, and to see this is not an isolated group.

Jerry Leonard The Lyme Disease Epidemic: CDC Tuskegee Experiment, Phase II http://www.publichealthalert.org/Articles/miscellaneous/tuskeegee%202.pdf

'As a result of the use of treatment guidelines to deny treatment, America's most egregious example of medical malpractice through treatment-denial is now an everyday reality, conducted on a grand scale, and run with the complicity of the CDC and other public agencies, which are exploiting the public instead of protecting them. I have referred to this as the institutionalization of the Tuskegee Experiment.'

Christine Keller Maine, we here without proper diagnosis and treatment liken the IDSA to Hitler, it is a fair comparison as you are willingly committing murder and life destruction to thousands upon thousands. You have no right, it needs to stop now, and you all need to FIX this immediately! I INSIST!

Kim Swann-King Christine, good idea, we all need to post where we contracted the disease. My Mom who has chronic Lyme disease, lives in the USA/Piedmont Triad area of NC

Susan Spicuzza Gray This disease has taken over my whole life. Yes...it is a true disease and please do something about this. Please help us find a cure

Brad Linberg Increased awareness and education for physicians and for students that will someday become physicians would be welcome. Besides a select few, many doctors I've encountered over the years have no idea chronic Lyme exists. The more who are aware the better. After 4 years of suffering from chronic Lyme and several co-infections, I now at least know a path of treatment.

Yemaya Theresa von Antropoff While you sit there in your ignorance & deny that Chronic Late Stage Lyme Diseases exists. I have been fighting for my life or even to have a life for 16 yrs. 10 yrs of going undiagnosed/misdiagnosed going from Doctor to Doctor only to be told there was nothing wrong that I was stressed, fat, needed a hobby, it was just a virus, etc, etc. I passed it on to both my children ages 13 & 8 yrs. Do you know what it is like to watch your children suffer & not be able to get them proper medical attention. Because of your denial & under education of Lyme Disease & other Tickborne illnesses. My family & countless others go on suffering. Right here on this thread you have thousands (Not to mention the many comments you erased) of people testifying that you are wrong. Wake Up, Get Your Hands out of Your Wallet!!! Recognize this Disease, & Change the Lyme Disease Guidelines.

Laurie Damsell Fahey RIP Leslie Ann Wermers Chronic Lyme Exists and Kills http://www.youtube.com/watch?v=NVsfGvZt-LA

Jennifer Dichiaro Grant IV antibiotics improved my symptoms however my insurance only paid for one month of treatment. I have been declining in health with oral antibiotic treatment. Please listen ...your guidlines are preventing me from getting the treatment I need. If I die it will be your fault!!!!! Please change the treatment guidelines so that chronic Lyme patients can get the treatment they need. DO IT NOW. Approve long term IV antibiotics, hyperbaric oxygen treatment, hyperthermia etc These treatments could make a huge improvement in my health. Thank You

Karen Smith If any other disease last more than 6 months it is considered a chronic condition, but not this disease. Why is it you admit that there are symptoms that can last months or even years after the 30 day treatment of antibiotics but yet every Dr I have seen after that 30 day mark has refused to help me with treatment. They only want to throw antidepressants at me telling me I am depressed and that is why I have chest pain, tingling, numbness, migraines, relentless joint pain, shin pain, blurred vision, fatigue, anxiety, heart irregularities, and memory issues (and these are just a few).

It is sad when because of your guidelines a general doctor or even a specialty Dr does not want a Lyme pt in there office. I have experienced this first hand. I am a Registered nurse and would not have believed any of this if I had not experienced it firsthand. It is shameful!!! I challenge you to prove us chronic Lyme victims wrong! Those who made the guidelines take the bite of the Lyme infected tick with some co-infections and deny yourself treatment for at least 6 years and see how that 30 days of antibiotics treats your disease! I have encountered the fact that I get sick and can barely walk when I come off any antibiotic. It may have not healed me yet, but what option do I have?? Do I function on antibiotics or do I lay in bed and get denied disability because they can't find anything else wrong with me and the problem being that there is no chronic Lyme so I can't get disability for the only thing I have been CDC diagnosed for-Lyme disease. Shame on all of you for leaving thousands suffer. Work together with ILADS and figure this out. Please !!!

Monique DeRuggiero IDSA guidelines are misleading. Acknowledge the wide range of symptoms (not just rash and joint pain), the fact that 3 weeks of antibiotics will not cure Lyme, and encourage medical doctors to test for Lyme whenever they see symptoms with no apparent cause.

Karen Golden My husband has been terribly ill for the past two years. Medical doctors cannot find anything wrong with him. He tested positive for Lyme disease in the states but cannot get treatment in Canada because you say this test is not legitamite. Please please have another look at Lyme disease testing and diagnosing. We cannot afford to get costly treatment in the states. You are our only hope to help him get his life back. We only ask that you do your best to help us. Thank you!

Louise Ashby The IDSA guidelines on Lyme disease and treatment are worse than useless. It is monstrous that this society has put itself in a position where it is working AGAINST the health and welfare of the public.

Denise OBrien Chronic Lyme is real here in Massachusetts. I got infected with Lyme in 2002. I never got treatment then. It's now 2012 and still have not received proper treatment. I never received any treatment until 2009 when I was bed stricken. I have Lyme in all my joints the pain and arthritis is unbearable, Lyme is in my heart and kidneys, it's in my nerves and in my brain.

I am one of the lucky Lyme people who actually have a few doctors that actually "BELIEVE" that you really do have "chronic Lyme" and they feel terrible for you because you are stuck in controversial red tape. These doctors have watched me get worse over the years, have seen my crazy symptoms, have seen my pain, watched this bacteria take over my body and mind at times, how symptoms change and the pain is overwhelming.

What hurts the most is that the treatment is out there but insurance companies won't pay because of all the controversy. This leaves people like me a single mother who was once a successful business woman...... So sick that you are unable to work because you may not be able to walk that day. Not only am I single mother my daughter is disabled and has down syndrome. I'm all she has. It makes no sense to allow people to get sicker. I need at least 18 months of iv antibiotics. I need longer treatment. 90 days is not enough. I need me back and to debate chronic Lyme does not exist. I'm living proof and I need my treatment to get well. If I don't get well WHO will take care of my daughter there is no cure for down syndrome there is a cure for Lyme. PLEASE. My life and my daughters are in your hands. Thank you for taking the time to read.

Elizabeth Leissner I would like to see Dr. Kempler explain in court how did he draw the conlcusions in the paper "Two Controlled Trials of Antibiotic Treatment in Patients with Persistent Symptoms and a History of Lyme Disease", in which the IDSA guidelines are based. -- he is a fraud!

Juliana King I would like to see people respected on here. You asked what you would like to see but then delete our comments? Look at the number of responses you have received that alone should say something.

Brittany Lyme Aware Agreed with everyone else about your "take" on Lyme Disease. It is definitely not "hard to catch" and "easy to cure". I've been battling it for the better part of 7 years. Misdiagnosed with many things-told I was crazy. Here's the crazy part though, after finding someone to treat me appropriately I'm getting better. I will likely never be completely normal again, however I am grateful for the few painless days I get. I've been called crazy, a hypocondriac, a drug addict, a liar, nuts...when all along I had Lyme and Bartonella riddling my body. Please look into the research that has been done. Talk to patients, listen to patients, do your own studies and realize our community is not crazy. This disease is REAL and DEVESTATING and KILLING many lives.

Kristen Kelley Please change your Lyme Disease standards/protocols and FACTS that you are misrepresenting!! SO many of us are suffering needlessly because of your backdoor politics and financial interests of the board members.

Kelly Pavelich The poor handling of the Lyme disease situation by the IDSA has opened the eyes of the public to the corruption within. By your suppressing of vital information you have willfully harmed the health of the public not just nation wide but internationally as well! Because of this we are now seeing the beginning of the end of medical self-governance and good riddance! What I hope to see this year are solid laws limiting your power and the power of the colleges.

Helen Vroman I would like for a real review of your policies regarding treatment of chronic tick borne infections as it does not support real time situations. You have a staggering effect on the physician population attitudes that directly impacts proper care and treatment with those of us suffering from tick borne infections. Your oath says to heal not harm and there are countless of us who have been harmed because of your erroneous stance. I don’t understand why you would deny treatment to those in need, maybe your research databases should match up to those who are front line tick borne disease researchers.

Ginny Coon Walcott *Can't add anything more than what has already been said above. I shed tears as I read about the destruction chronic Lyme has caused me and thousands, if not millions, of others. Insurance denied the use of IV antibiotics for me ... and so I continue to suffer the ravages of chronic neuro Lyme disease. My prayers go out to all of us.*

Marisa Borg Tell me why, if I don't have "Lyme disease or Co infections," I can exercise, get out of bed in the morning again, think clearly, not have numbness, tingling, pain and a host of other problems after a year and a half of antibiotics! Some of the most effective antibiotics were denied by my insurance, causing us to spend thousands of dollars out of pocket for my health. But no thanks to your guidelines, I biked 100 miles this summer....Time for you all to figure out what you're missing so innocent adults and children stop suffering and being told they are crazy and that Chronic Lyme doesn't exist! People are getting well on ILADS guidelines,not yours!

Kathleen Crowley Babineau I would like to see a change in the guidelines, so doctors can start treating Lyme without fear. Let us not have to suffer anymore.

Kerry Roushey All we want is the "proper" treatment of Lyme disease.. It's all we ever wanted. Just a chance in hell to have some sort of normal life and feel a little better.. The IDSA has done nothing but stood in our way.. I have seen so many friends die.. and others just wishing they would. For once, help us. I can assure you, none of us would mind being guinea pigs if you would at least try.. and if not, then take a step back so other Doctors can try. Why have we been left behind? What have we done bad to deserve this horrible treatment we all receive from your Infectious disease Doctors? We just want to get better like everyone else with any other disease.. we just want a chance.

Kristen Kelley Upstate New York - Albany area

Terry Ingels Sutton Change in policies in regards to Lyme disease and treatment of Lymes. Why is it that people who have contracted Lymes are often miss diagnosed and can't get proper treatment. Why is it that because of you insurance companies don't cover Lymes and won't pay for treatment? There needs to be a change, and it needs to be done NOW!

Nicole Randazzo HOW ABOUT THE TRUTH? I am shocked by the amount of LIES and the lack of TRUTH related to the IDSA Lyme and related co-infection guidelines. If YOU are bitten by a tick, I pray that YOU do not follow your own advice. You are harming people with all the lies and should be held accountable for your actions. My first tick bite was when I was 12 years old and since I have had untreated Lyme since 1980 and my two children also have Lyme. We didn't know it until 26 years later. When I was bitten by a 2nd tick 7 years ago I read all the wrong information and was told that since I did not have a bull's eye rash and tested negative I was not going to get sick. Well, that was a big LIE! 2 years of begging 20 different Long Island doctors to help me, not one of them would treat me because of exact the same reason that you guidelines are all LIES! My visits to an ILADS Lyme Literate Doctor, 30 months of several different combinations of antibiotics and I am now well. I have the right to choose my treatment and decide for myself. We know the difference between YOUR conflicts of interest, financial gain and OUR health and well being. I am well and with absolutely no thanks to the IDSA, AAN, CDC or any of the doctors who denied me treatment. The members of the IDSA should be in jail for their mistreatment of Lyme patients and the misinformation you are publishing about Lyme and the co infections that not only Deer Ticks can give you. If you go to www.ILADS.org, you will get the real facts and information about Lyme. If I had listened to your recommendations, I'd still be sick, on disability, perhaps have no memory of who I am or suffered a slow painful death from my muscle nerves and joints being attacked by bacteria that could have been treatable with the RIGHT combinations of antibiotic. Thankfully WE are smarter than YOU think and WE are spreading the TRUTH about the IDSA, AAN and CDC. SHAME ON THE IDSA!

Deb Daniels Lerew I don't ever remember getting a tick bite or seeing your classic "bulllseye" rash, but I can tell you the exact day and time I began having symptoms---June 1, 2008; 10:30am. My neck began hurting so badly I could barely move my head, I began feeling light-headed, and then my left side went completely numb on me. I walked over to a chair to sit down, and I felt as though I were walking on rubbery legs. I was checked for a stroke; thankfully it was not. Over the next NINE MONTHS, I endured test after test from every kind of doctor you can imagine, yes, even two Lyme disease tests. When those doctors couldn't find anything, they just attributed my symptoms to a midlife crisis, stress, anxiety, or just a desire for attention, even though my family doctor had known me for years and knew I wasn't that type of person. When I finally connected with a Lyme-literate doctor who diagnosed me clinically with Lyme, babesia and ehrlichia, and began treating for those tings, I finally got at least some of my life back. I am finally to a point where my disease is in remission, although I still have symptom flares.

What I want to see from IDSA, and from the entire medical community, is an acknowledgement that Lyme is NOT easily diagnosed, does NOT have certain specific-to-all symptoms, and is NOT completely cured with a couple weeks of antibiotics. I want doctors to be allowed to diagnose Lyme clinically as they do with other disease, such as CFS or lupus, and to be allowed to use long-term antibiotics to treat tick-borne illnesses without fear of being punished by insurance companies or reported for abusing medications. I want to see awareness raised in the treatment and prevention of Lyme and other TBIs. Really, is that too much to ask?

Stephanie Dean Sloan I would love for guidelines for Lyme disease.....late stage or chronic however you want to name it be established for physicians all over the United States to follow. Lets get rid of politics in our medicine and truly beat this stealth bacteria! Let us get rid of conflicts of interest in this regard as well with board members who serve on IDSA board. Best of luck and hope you will listen to those of us with late stage Lyme disease treatment.

Christine McKeever Ryland A change in the current guidelines concerning Lyme disease. To really look at all the research done, LISTEN to both patients and those medical professionals who have TREATED thousands of patients. Pleaes get in step with what is really happening out there with tick borne illness. I hope this is more than a 'wish list' but will be a 'reality'

Ginny Coon Walcott Can't add anything more than what has already been said above. I shed tears as I read about the destruction chronic Lyme has caused me and thousands, if not millions, of others. Insurance denied the use of IV antibiotics for me ... and so I continue to suffer the ravages of chronic neuro Lyme disease. My prayers go out to all of us.

Shauna Mowers Why are you DELETING post? Myself and several others have been deleted. I just stated facts and concerns.

Sue Austin I'd like you to fire yourselves and support an indepent advisory committee as outlined in H.B. 2557 and S. 1381 -- an unbiased committee with no conflicts of interest and a broad range of scientific and medical experience with the input of LD patients to sincerely and urgently work toward research in treatment and diagnostic testing, education, access to care, and provide funding. . . I'd like to see the members of the IDSA Lyme advisory board to open your minds as wide as your wallets. I'd like to invite you inside my body and my head -- the only correct thing doctors denying chronic Lyme may have said that's right is it is in fact in my head in my brain.

LD is not hard to contract and it is not easy to treat -- but these statements might be turned around on day if proper funding and research allows for the research and education necessary to treat those already infected and prevent the infection in others. It breaks my heart when I hear of another person infected. If you are one of the doctors or scientists who believe chronic Lyme disease does not exist -- infect yourself with a tick carrying Borrelia, Bartonell, Babesia, wait at least a year for treatment, and take a short course of antibiotics. If you have the cognitive ability to report back, let me know how you're doing. Shame on you, IDSA.

Wanda Golsan Recognize Lyme disease!!

Shauna Mowers You say you are our society and asked us what we wanted....but then you DELETED our post. WHY? If you are our society you should listen to us. Please don't delete honest post.

Renatta Sinclair Welsh I have 2 family members diagnosed and struggling with Chronic Illness in this last year. Please give more attention to Lyme as well as the emerging disease called Protomyxzoa Rhuematica. Thank you.

Sue Austin Call, write, email your congressman and urge them to co-sponsor and support House Bill 2557 and Senate Bill 1381 to establish an independent advisory board. Here's a link to make it easy for you: http://www.Lymedisease.org/news/Lyme_action_alerts/ldaalert.html

POLITICAL ACTION: Contact Congress about this Lyme bill
www.Lymedisease.org
Help sign up co-sponsors for HR 2557.

Patrick Wylie Kelly Involve the top LLMD's in establishing guidelines. Beginning with better testing and fight for non-labcorp tests to be covered by insurance. Working with doctors establish comprehensive treatment guidelines using both pharmaceutical and proven natural-dietary-herbal methods.

Denise StGermain
http://whatisLyme.com/rest-in-peace/

Rest In Peace
whatisLyme.com
People who have died of Lyme Disease

Donna Smith Hemphill contracted Lyme in Irmo, SC in 2007, diagnosed CDC positive in May of 2009. Still sick due to lack of treatment. Insurance won't pay for Lyme disease treatment beyond 1 month. Looking for respectful dialogue between the two societies and establish less restrictive guidelines that won't hinder our doctors and opens the door for insurance companies to pay for treatment. There are many patients with other diseases that have had to fight for treatment (cancer, HIV) before appropriate changes were made, we are no different. The data is available to confirm various treatment wins, take them seriously and change accordingly. Thank you.

Suzanne Longmire Williams The truth about Lyme. Give patients respect and listen to them. Do not restrict treatments to anyone. Be positive, this is not a battle to take sides over. This is about the health and well being of People! Thank you!

Janet Jensen Recommendations to clinical laboratories to report intesnity values with Borrelia ELISA and Western Blot tests and the normal ranges (as is done with other laboratory test reporting) as opposed to current practice of "pos" or "neg", and inclusion of all WB bands. Would like to see FDA or ASTM establish test standards against which commercial kits can be validated.

Sharon Petriello Meier So good to hear people speaking out! I have been suffering with Chronic Lyme disease for over 4 years and it has been debilitating! Has totally changed my quality of life.....we need support!!

Kim Cohlmia Musgrove Please recognize Lyme disease so people can receive help that they need.

Debbie Kushner In 2012, I would like to see the IDSA focus their efforts on Lyme disease and its associated co-infections specifically Babesia and Bartonella. Stop ignoring the group of people that DO suffer from chronic Lyme and associated chronic infections. While a vast majority of people do recover quickly from Lyme, there is a small percentage that don't. Please stop ignoring the people that are suffering with chronic infections, your ignorance is ruining lives. There is a growing epidemic of Lyme and associated co-infections this topic was considered one of the Top 25 Under Reported stories of 2012, see #21 in the link below. http://www.projectcensored.org/

Julia Bjerre It would seem to me by the sheer volume of responses, the Lyme community is not receiving the proper treatment they need and deserve. I wonder if you posted another question asking how many long term Lyme patients had recovered following your protocol, how many positive responses you would get? Why not give it

Julia Bjerre Why not give it a try? We are telling you the current protocols do not work....show us they do by asking cured patients to post.

Phyllis Shaw My sister was bitten by a tick in April 2006. A week later she got sick and was put on 10 days of doxycycline, 200 mg daily. Got better but then two months later she was very ill. By July she could hardly walk, was in severe joint pain and dizziness. She went to about 15 doctors who could find nothing wrong with her, the standard lab tests for Lyme, Lab Corp & Quest were negative, Dr's told her she was just getting old, had mental issues, etc. We finally got her to a LLMD. Her IGENIX tests were highly IGM positive for Lyme bands not tested on the WB tests from LabCorp & Quest. She was on antibiotics for nine months and got well!! Something is terribly wrong with the ISDA guidelines. I have seen many people get WELL once they got treated by a LLMD. Doing away with the old ISDA treatment guidelines will save BILLIONS in SS disability, medicare, unemployment and welfare benefits. From the research it is highly obvious the people who will lose are the ISDA researchers, Steere, Wormser, et al. What happened to "Do No Harm"? Plenty have been harmed by the ISDA guidelines and persecution of Doctors treating Chronic Lyme with long term antibiotics.

Phyllis Shaw Plus i have lost TWO friends to Lyme in the past six months. Both were diagnosed with ALS, only to find out later on they actually had late stage Lyme, too late for the IV ABX cure! Early diagnosis using IGENIX and prompt treatment by a LLMD saves lives.

Heather Brookins Yes, Please start trying to help save people starting with the lab testing for Lyme. Maybe you can also try educating our medical doctors who know nothing about this disease. Recognizing the research that has already been done on Lyme disease would also be a great start to the new year. Maybe after you read all of these comments you will also discover that Lyme disease has become a pandemic across our country and is not being treated as such.

Patrick Mullen Lyme is in every state. Educate yourselves. These thousands of sufferers are the reality.

Mary Delisser and in every province in Canada

Diana Allen I would like your organization and our nation's governmental agencies responsible for the public 'health' to acknowledge the true threat LD (and co-infections, of course) pose to the USA and world. Only then will we be able to be response-able in more honestly stating this true threat to national health and security. I would like THIS YEAR- IN 2012-to finally to see the lying stop and the truth be told about effective diagnostic & treatment options that could save lives in the treatment of Chronic Lyme and co-infections. If the 'powers that be' – ie: our government, insurance companies and organizations like yours – don't tell the truth about this pandemic, such entities will be truly responsible for millions more needless cases of human suffering and death. Billions of dollars could be moved from lobbying against this disclosure into research and services to care for and even possibly HEAL the millions of folks who suffer needlessly w/ LD.

Debbie Kushner Phyllis - I'm sorry you lost friends to Lyme. I've read about Lyme being misdiagnosed as ALS. There is also a growing epidemic of Bartonella. Dr. Edward Breitschwerdt of Duke University runs a testing facility called Galaxy Labs that is doing some ground-breaking work. The problem is too few doctors check for the co-infections PLUS the tests available in the mainstream market aren't checking for all of the strains of Bartonella that cross over the zoonotic barrier. What a mess.

Kellie Loerzel I would like to see the guidelines for the treatment of Lyme disease be changed and our suffering noticed. In 08 after being bit by a tick i did nothing. it took only 4 months for me to get very seriously ill with excruciating pain, chest pain, tremors, shaking, headaches, vertigo and so on and so on. i believed and listened to my drs here for two years who followed your guidelines only to get sicker and sicker and end up hospitalized with meningitis and told i needed to get my health better or i could die. i began treating with one of the best llmds and with long term antibiotic treatment and picc line and IVs i am oh so much better. i feel great. except the red tape of this disease has destroyed me more than the disease itself. you cannot imagine how we feel, like every day is the worst stomach bug you every had, the worst flu you ever had, the worst mono you ever had, the worst blood poisoning you ever had, the worst pain, and the symptoms go on and on. You can't imagine it and say that treatment is like a sugar pill. Those feelings of sickness are totally disabling and no one person could fake them or pretend they exist and after not know for 2 yrs about Lyme then how could I have faked being ill. It's not a few aches and pains, its 2 million times that. please do something so others don't have to go through what i did. And yes i did test pos 4 months later and two years after that.

Jen Schuler Please change the guidelines so that Lyme disease can be adequately diagnosed, treated and covered by insurance. It is absolutely tragic that children and adults suffer so much pain and disruption to normal life with such a difficult road to getting any sort of help at all when answers could actually be available. No child should be left to suffer in this way because of flawed guidelines.

Jerry Leonard why are more than 20% of the IDSA Lyme Guideline authors biowarfare researchers?
https://sites.google.com/site/jerryleonard999/home/what-s-wrong-with-this-picture
What's Wrong With This Picture? - winstonsmithspeaks
sites.google.com
medical ethics and human experimentation

Ken Hess The TRUTH about chronic tick disease, ie that it EXISTS and is disabling thousands of people. Updated guidelines on how to treat chronic tick bourne illness, including the possibility of years worth of antibiotics and antimicrobials. Recognition that it may be the underlying cause of many chronic illnesses such as CFS, FM, MS etc. C. Hess (a long time sufferer of tick disease--bitten in childhood and untreated for decades--now seeing a Lyme literate MD)

Teresa Williams Young I want to say a lot of things to your organization, but I'll sum it up with this: you have all sold out to big Pharma...not sure how you can sleep at night. Chronic Lyme Disease & it's related tick-borne infections DO EXIST, they DO KILL & MAME, they ARE RUINING PEOPLE'S LIVES. Please acknowledge this & stop all the misleading guidelines. You know the truth. Stop allowing money & greed to shield your vision. Please do the right thing here & GET HELP to those of us who are suffering from this debilitating illness. I also pray none of you ever get bit by a tick & get Lyme, as I wouldn't wish this on anyone.

Patsy Swinson You should be wondering why the most knowledgeable doctors on Lyme Disease are not even Infectious Disease Specialists. That should tell you something. There's a growing epidemic of Lyme Disease, which is an infectious disease, and yet infectious disease "specialists" know less about it than many of us who have no medical training at all. That should concern you. The evidence is abundant and undeniable. Why aren't you embarrassed that people are dying who your specialty could be helping? It is shameful and disgusting that your ignorance, special interests, and pride is more important to you than people's LIVES. You have no conscience.

Debbie Kushner In 2012, please consider a greater focus on Bartonella. This bacterial infection is under-diagnosed and under-treated. It is NOT treated by the same antibiotics that treat Lyme, but CAN be treated concurrently. Bartonella is NOT self-limiting in ALL people, especially those with other infections and reduced immune systems.

Jill Wallace Obviously, there are so many tragic stories of people suffering needlessly with Lyme Disease and co-infections. Although I do not have this horrific disease, I live with it every single day. It is not just the people carrying the disease who suffer...those of us who love and care for someone with this disease also suffer immensely. There are no words to describe how helpless we feel watching our loved ones go through so many horrible days...The cases are under reported because of misdiagnosis, politics, etc...but, I can tell you that tens of thousands of us are affected by this disease. Please do the research and find a cure; in the meantime, please update your guidelines to allow doctors to treat this illness and reduce the suffering for all affected.

Larry Betson An honest evaluation of Lyme disease and the treatment for chronic Lyme disease. Myself and many people I know have suffered with this terrible disease for a very long time...it's epidemic and not in our heads.

Lena Elm i've battled Lyme for several years, tested positive, met the strictest CDC criteria for case surveillance (bulls eye rash) and clinical findings still ignored and abused for years. for lack of physician education, and lack of research, insufficient treatment with INEFFECTIVE DRUGS and the Coverup, the result of it. I HAVE ALZHEIMER"S at years old ... when do you stop serving your own interest, and serve us? the millions of us suffering battling Lyme and our children, and the hundreds of thousands that'll become infected each year!!! Where's your conscience? are you even human? Shame on you!!!,how can you do this to the millions of us ...standing by watching us suffering and dying slowly... or you're just neglecting us because you know of TRAUB's invention that left millions of us victims of Bio warfare ...step up to the plate for ONCE and do the right thing ... Help us !!! You wouldn't be able to walk in our shoes for a mile let alone a lifetime ... WARNING: whoever is reading this press, LYME CAUSED MY ALZHEIMER"S what supposedly they call ALZHEIMER ...IDSA hear our pleas for once!!

Simo Heger Unterstützung!!!

Anna Maria Castello-Barraco I would like you to take a look at every one of these comments and realize that each of them represent a real person whose life has been destroyed by Lyme; That we have been denied treatment, mocked by doctors, and called crazy. It's time for IDSA and the majority of doctors to get off their pedestals and stop looking down on us like we don't know what we're talking about. I worked as a medical assistant for 10 years. I know exactly how doctors react.

When an "informed" patient leaves the office the doctor scoffs and curses the internet for providing information to patients. IDSA need to admit that they are not infallible. It is disgusting that with all of the proven correct information out there that these doctors can't admit that they have more to learn. Wasn't it only 100 or so years ago that the most common treatment for diseases was "bleeding"? The medical and scientific fields are ever-changing. It's horrific that the patients will be the ones who suffer and die needlessly while the doctors, insurance companies, and the government stand there with their fingers in their ears like tantrum-throwing toddlers who refuse to listen to reason.

Puma Of-Thenorth Until the CDC as well as the IDSA adapt truthful guidelines for Lyme disease they are harming the people of the USA daily. Not being able to receive a truthful diagnosis when gravely ill can destroy lives bank accounts relationships & in some cases be fatal. Not only are their misleading guidelines for Lyme disease & co-infections used in the USA they are used in other countries as well. This travesty is clearly abuse on the part of the people like Wormser & Shapiro that know better yet allow these lies to continue for their own perverted financial gain. I pray that one day this insanity will end.
“It's really a wonder that I haven't dropped all my ideals, because they seem so absurd...Yet I keep them, because in spite of everything I still believe that people are really good at heart. I simply can't build my hopes on a foundation of confusion, misery, and death...and yet...I think...this cruelty will end, and that peace and tranquility will return again. ”
Anne Frank

Carol Payne Official recognition of Chronic Lyme Disease and more research and doctors who know how to treat it.

Neil Huey I trust this post will not be removed as it is available under the freedom of public information act. The antitrust investigation of the ISDA by Connecticut State Attorney General... (which was settled out-of-court for the promise of consideration of all available scientific data of merit and to convene a new and independent panel)... began in mid 2006 and concluded April 22, 2010 when the new ISDA Review Panel concluded... "Guidelines are not intended to be (and cannot be) rigid dicta, inflexible rules, or requirements of practice. 46 Gonzaga Law Review, 117, Jan 31 , 2011, Unprecedented Antitrust Investigation into the Lyme Disease Treatment Guidelines Development Process.

June Whitehead we are sick and angry why won't you help us! Why are you letting children suffer and die???

Susan Reif LISTEN to all the comments posted here and take action NOW. Action towards what is actually happening with vector borne diseases in our society. Nobody will admit that we have a pandemic right here in the U.S. right now with Lyme Disease. People are having long term illnesses, YES there is late stage Lyme Disease. Babesia is invading our blood supply, how severe does it have to get?? I can't understand the IDSA's ingnorance that has existed, and continues to exist. Just follow all the digital data that is flowing today - it will tell you the true state of your citizens. All government agencies that address disease need to step up and do something, I find it ironic that the U.S. Agnecy for International Development (USAID) is funding research to map worldwide animal disease outbreaks that might threaten human beings, when we alreday have an outbreak on our soil. We have seriously ill Americans that are suffering in all states!! Yes, Lyme disease does exist in California - I am going on 20 years.

Angie Rowell Miles-Moore Official recognition of Chronic Lyme Disease and allow more doctors to learn and treat this Epidemic !!!!!!! it is very sad that we live in the Great Country of the USA but cant get treated properly for Lymes ...

Bobbyjoe Holliday what ever happened to the C.D.C. study of Morgellons Disease that was finished years ago & they are silent still, can anyone answer this or is their corruption in our Government agency's that show now responsibly to it's people of a Country where we are supposed to be free, where is the freedom we are supposed to have I ask all of you?????

Cheri Clark I would like Chronic Lyme Disease to be accepted as real. Not everyone who has Lyme disease ever had antibiotics cause they didn't know they had been bitten or, like me, I was in California in the 70's and didn't think there was Lyme in the tick that bit me and never got a rash. Finally in 2009, a wise Dr. took a blood test, now I am on low dose long term antibiotics and getting better. Please be open to reevaluating your lab protocols for detecting borrealis in the blood!

Bobbyjoe Holliday where is the Justice we are entitled I ask?

Phyllis Shaw Debbie, very interesting new info on Bartonella, I am aware it can be treated with Rifampin, etc. Also there are herbal formulations that have helped some bartonella sufferers. As you say, it’s not just Lyme its the co-infections and co-nfection testing is notoriously unreliable for many reasons.

Bobbyjoe Holliday this Country talks about the unjustly things of other Country's & denies it's own people the justice we all deserve, what Hippocrites!!

Debbie Kushner Phyllis - I am taking Rifabutin rather than Rifampin b/c it has less issues with side effects. Added bonus, it gives your skin a lovely glow!

Maria Angeles Gómiz Maillett Review your guidelines for testing and treatment of Lyme disease so Dr's can follow the right treatment before it's too late.

Kelly Mairson Deleted :-(
And I was super nice

Michelle Frey Hellenbrand LYME disease and its co-infections are chronic long-term illness. Finally diagnosed in July of 2011. Been misdiagnosed for almost 2 decades. Passed to both of my daughters while pregnant.

Michelle Frey Hellenbrand OWN up to your mistakes! Recognize TBI for what they are. FUND the research, bring AWARENESS! Get behind us and support us!

Billie Hensley Brooks Help to get Lyme Disease recognized by the CDC.

Joni Comstock ~~~Please help those who suffer from LYME disease & M.E. We NEED more research, more sensitive tests, education for health care professional & the public, better treatment & a CURE!

Shauna Mowers Please start acting for the good of us rather than the harm....educate the ID doctors to identify and treat Lyme Disease early on. My daughter went to 3 different ID doctors who all insisted she couldn't possibly have Lyme because it either did not exist in CA or she had already been on antibiotics for a month and should be well. We had one ID doc even refuse to see her because we said she had Lyme. My daughter has had well over $200,000 in medical bills because she was not diagnosed for over a year. If she would have been diagnosed when she was first sick, not only would it have saved money....it would have saved her life. She has no life right now...not even able to attend school. She can't even get out of the house most days....no life for a teenager, or anyone.

Michelle Frey Hellenbrand *LYME disease and its co-infections are chronic long-term illness. Finally diagnosed in July of 2011. Been misdiagnosed for almost 2 decades. Passed to both of my daughters while pregnant.*

Penny Taylor Recognition of Lyme in Texas by Texas doctors and their education and support by the TMB to treat the thousands of Texans suffering from Lyme Disease and coinfections. Lives have been lost, wasted, and are not even properly diagnosed becaused this great imitator - Lyme Disease - is not recognized here in Texas. And I should know - because we are a family of 3 that have been infected and suffered greatly both physically and financially.

Diane J. Marie When a child or an adult contract Lyme disease, it has been the mission of the IDSA and nearly every infectious disease doctor in the country to make sure that they cause that patient to develop CHRONIC Lyme disease, a horrible, frightening and in varying degrees debilitating illness. And here on Facebook, the IDSA has the gall to ask, "What would you like to see from your society in the coming year?

Diane J. Marie Here's what I would like to see in the coming year: STOP IDSA CORRUPTION AND LET LYME PATIENTS OBTAIN TREATMENT THAT IS KNOWN TO HELP THEM. KIDS AND CHILDREN CAN DIE FROM CHRONIC LYME.

Emily Mowers Better guidelines and treatment available for Lyme disease patients.

Robert Pierce A collaboration between IDSA and ILADS.

Linda Marotta McGee Don't know where to begin.....I will start with THE CHALLENGE. I would like to challenge every IDSA doctor who has said there is no such thing as chronic Lyme disease and have made guidelines making it impossible for doctors to treat Lyme without fear and insurance companies to pay for treatment to take my challenge. If you are so sure there is no such thing as Chronic Lyme then are you willing to inject yourself or a loved one with the bacteria of an infected tick, co-infections and all, wait until it gets to stage three disseminated, then just take 21 days of antibiotics and see how you feel. It's not gonna be pretty!!!

Since I was diagnosed 8 years ago, this disease has emptied out our savings account because insurance did not pay for my treatment or doctors appointments. It has destroyed my families' lives as well as so many lives!!!!! This is my story.... I have had various medical issues since I was 5 and lived in an epidemic area of MA. My parents pulled ticks off me all the time. That is when she said my whole personality changed. All my adult life, I have lived with medical issues and no doctors could find anything wrong until 8 years ago when I moved to Leesburg, VA (now Northern Virginia is no. 3 in the country for Lyme cases). I did the gardening at my home, never saw a tick or had a bullseye rash, just became ill for about 18 months and my doctor couldn't figure it out. Finally ended up in the hospital with white blood cells a 2, infections in my spinal fluid, loosing my sight, muscle spasms, light headed and did not have enough strength to get out of bed. GUESS WHAT, WESTERN BLOT CAME OUT NEGATIVE!!!! Thank goodness for an infectious disease doctor who treated me with IV antibiotics without a positive.
During the treatment I went to see one of the top Lyme Literate doctors in the world. Dr. Bernard Raxlen. When he sent my blood to IgenX lab, GUESS WHAT, I WAS 8 BANDS POSITIVE AND HAD 2 CO-INFECTIONS. It took me 2 years to get better. I was doing OK, but you can't ever forget you have Lyme. I did. I pushed it teaching 40 hours a week and taking care of my 3 children and home. Started to feel bad but ignored it and then ended up with a relapse that caused a permanent heart arrhythmia. I can't work and financially it has completely drained us. WHEN WILL THIS END, WHEN WILL INSURANCE START TO PAY, WHAT DO WE HAVE TO DO?

Rachel Andrews Brakel Dear IDSA-Please do some research on Chronic Lyme disease (and share it with your member doctors!). There is more than enough evidence to support it's existence and severity; you just choose to ignore the evidence in the name of ego and money. Your patients' lives are more important than that. Please wake up and recognize all of us who need help. 3 of our 5 family members are currently being treated for Lyme, including our poor precious 4 year old who most likely contracted it from me. We have had numerous doctors over the years of going through this tell us we were crazy, etc. Mostly my husband, who was always a strong and healthy athlete.

In his late 20s he was reduced to lying in bed for endless months with a mystery disease that none of the 20+ doctors we saw could identify. Thankfully we heard about Lyme through a family member. We were able to research it and find competent doctors to help him. 3 years later, he is still battling. But...he is alive, and we're so thankful for that. Had we not researched Lyme on our own and sought appropriate treatment, I have no doubt that he would no longer be with us. Please wake up and reach out to help families like ours who are living in the trenches with this horrendous disease. My husband especially could have endured much less suffering if any of the first 20+ doctors he saw could have identified what was causing him so much harm.

You asked what we would like to see, and we're answering. I've noticed that the vast majority of people answering this question are begging for some legitimacy concerning Lyme disease. Please step up to the plate. Thank you.

Anna Silliman After two years on oral antibiotics I am finally recovering my health after many years of suffering. It seems I have both Lyme and bartonella. My advice to the IDSA is: get some reality. Look at the good science that contradicts your stance. Learn about the successes of LLMD's. Once better testing becomes available, the truth will be known and what you are doing will go down as the worst crime in medical history.

Kristin White Slye For IDSA to take Lyme seriously and consider the facts.

Lucina Botond I would like to see you include in the reevaluation of your guidelines on Lyme Disease the expertise of doctors who treat chronic Lyme Disease on a regular basis.

Phyllis Shaw Penny Taylor - Amen, yes family has to go out of state for treatment! Join the TXLDA if you haven't already.

Melissa Rascio I would like for all of the doctors treating Lyme based on IDSA Guidelines to lose their medical licenses due to malpractice. They could have treated us, but chose not too! Where are your responses IDSA!?!?

Shelley Senkbeil Truth and help for all Lyme patients in America. Acknowledgement that chronic Lyme is REAL!!

Cris Venosa Recognize Chronic Lyme Disease and change your guidelines!!!!

Brittany Reeve Here in Boise, Idaho we want you to recognize Chronic Lyme Disease and change your guidelines!!!

Al Ex I'm not going to banter on about how Chronic Lyme is an absolute or about how your theory of a Post-Lyme Syndrome is an absolute. There simply is not enough research is either direction to conclusively support either theory.

Aside from doing more research, the responsible thing to do is for your organization to revise its guidelines to be far more flexible. Make them guidelines, so to speak; rather than a list of strict rules where state boards crucify MD's for not following them to a tee. Let doctors practice medicine again.

My two primary concerns:

-The efficacy of long-term antibiotics: I've seen it work. At the very least, allow the primary care provider to consider this form of Tx on a case by case basis. Just because we cannot find the Spirochetes does not mean that they are not there. If the patient gets better, doesn't that provide enough evidence not to completely dismiss the efficacy of this style of treatment?

-Your emphasis on diagnostic tests: the existing tests are not accurate. The diagnosis of Lyme Disease should be based primarily on clinical findings.

Medicine is a dynamic field, obviously. There's a lot of pathological mechanisms that we still do not fully understand. Lyme is no exception. Making such stringent guidelines is counterproductive to moving ahead and being progressive. Doctors went to med school too. Let them use their clinical judgment and decide what's best for their patients.

Anja Maurer Dear members of the Infectious Diseases Society of America:

Even if your Lyme-Borreliosis guidelines are not affecting me directly, they affect me indirectly.

I am from Germany and our guidelines are based on the IDSA ones and they bring tremendous suffering in Germany too – in terms of refusal of appropriate therapy by clinicians, to name only one. In Germany too chronic Lyme is negated, downplayed and ignored. I therefore hope that you change your guidelines according to the newest state of science, that you recognize the chronic form of Lyme disease and that you discard the 2 week antibiotic therapy as gold standard.

Instead the clinicians training should be strengthened, research must be accelerated and the reams of Lyme patients around the world must finally be heard and taken seriously.

Neil Huey Wife was dx w/ ALS...no familial ties, no environmental or chemical exposure, but there was a pathological pathway...a bug bite, determined much later to probably be a tick due to unexplained rash. Years later positive for Lyme, suspected babesiosis,

barontella, ehrlichiosis. After many years of fighting for her rights as a patient (ironic as one time she was head of an ICU and acting head of CCU) fighting insurance companies to get proper care, fighting social security because of disability denial, but most importantly fighting for the dignity she deserved...she passed away. It takes a unified medical community to advance medicine.
To no fault of the ISDA, but by unintended consequence, more physicians (with the necessary medical intellect) would have treated tick-borne disease if it were not for fear of license revocation by state licensing boards initiated in part by pressure from insurance companies because the physicians were outside of expert guidelines (which coincidentally may be convenient for some). I ask how clear and prominent has your recent disclaimer to the 2006 guidelines been made?...and I quote from new ISDA panel April 22, 2010...."Guidelines are not intended to be (and cannot be) rigid dicta, inflexible rules, or requirements of practice." 46 Gonzaga Law Review 117, Jan 31 , 2011. To some that may be rather obvious.

Carl Tuttle The online petition against the IDSA member's Lyme disease study has gathered 129 signatures from across the US, Canada, Germany, UK, Ireland, Belgium, France, and the Netherlands. Please take a moment to read why people are signing this petition.

There are now seven states which have passed legislation to protect clinicians who treat late stage Lyme with long term antibiotics (CT, RI, MA, MN, NY, NH, and TX) and there are support groups in nearly every state with nineteen in Pennsylvania alone.

If the IDSA and CDC got it right with their "one size fits all" treatment approach for all stages of Lyme disease and faulty two tier test algorithm why then do we have this much legislation involving Lyme disease?

Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-Lyme-disease

Carl Tuttle
Hudson, NH
Website:
http://home.comcast.net/~runagain/site/?%2Fhome%2F

Stephanie Vandagriff Really!? I tell my story and you deleted it! WTF. I will retell my story because you can't silence me. For 20 years my father and I have gone undiagnosed. Because of this, my dad and I have permanent damage. You have robbed my childhood and my young adult years from me. I'm now housebound and I'm only 30 years old. My decision in life now is deciding if I do something normal is it worth being sick for a couple of weeks after. You have robbed me of my life. I hope you sleep well tonight, at least one of us should.

Phoebe Klemz yesterday there were 1,600+ comments, now it shows 1,400. how many are there really?

Kaethe Mitchell Why does your "Recommendations" feature on the right of this screen say there are 22 recommendations, but only 6 appear when I click "See All"?

Trish McCleary I would like to see the IDSA allow education to physicians from organizations on the frontlines who are researching and treating Lyme disease and co-infections associated. Allow the knowledge to infect the IDSA so good can come to the millions affected by this epidemic! It's time to allow the change to happen and for the IDSA to be part of the solution...

Deb Anderson Eastman Let me add one more! I run a Facebook Group called Beating Thyroid Disease with LDN, and I cannot believe how many folks are finding out they also have Lyme Disease! How is this possible? Are you underestimating the number of folks with this Scourge to Humankind? I, for one would Really like to know!

Susan Spicuzza Gray Well said Patsy Swinson!!! Why do we have to learn to treat ourselves? We are all broke from trying every remedie under the sun because we are so desperate to be well. Some of us can't even afford to see a Dr. anymore or try another pill. WAKE UP!!! This disease is an epidemic. When will you open your eyes to this? Will it take one of your loved ones to become as ill as we all are. Find a cure before that does happen.

Madison Lewis Please stop deleting the most educated and important, eye-opening comments of these Lyme Victims. it's too late to try to keep the # of comments/hits down. It only makes your hands look dirtier than they already are. We are covered by the

Freedom of Information Act, and as far as FB criterium, the deletes have been more than acceptable.

Wanda Stibitz I have never been treated so rudely by a doctor! And not even knowing what a co-infection to lyme was!!!! It seems that the only doctors who believe in accurate lyme treatment are those that are personally affected! I do not wish this on anyone but maybe some IDSA docs should put themselves in a lyme patient's shoes before it happens to them! The IDSA should hang their heads in shame!!! I have now been suffering for 9 years because of an IDSA doc's incompetency (& getting better with long term treatment and treatment of co-infections too!) Wake up before it gets you!!!

Margie Noyes Donohue eliminate the devastation of Lyme disease by recognizing it as a legitimate diagnosis

Mary Virginia What I desire from your organization is acknowledgement of the existence of Chronic Lyme disease and recognition of the degree of debilitation that it causes its sufferers.

Christine Heffer I too am infected with Lyme and co-infections -- changes need to be made in how this disease is treated

Trish McCleary For help with Lyme go to www.lymediseaseassociation.org or ILADS.org

Shannon Fisher I would like not only the legitimate recognition of Chronic Lyme (and its appropriate long-term antibiotic and anti-parasitic treatment) but also adding information on the diagnosis and treatment of Chronic Lyme to the mandatory curriculum for continuing education of general practitioners, emergency room doctors, rheumatologists, neurologists, internal medicine specialists and -- of course -- infectious disease specialists.

Molly Cap Accurate testing on Lyme Disease and it's co-infections as well as real treatments for main stream doctors. Please help us.

Sonnen Schein I'm from Gernmany and I want you to change the IDSA guidelines. Longer treatments and recognition of chronic Lyme disease. We want more research!

Deb Compton-Venezia I'd like to see better guidlines and treatment for everyone in need of better, more affordable healthcare. I'd like to see you take Responsibility for the Fiasco that we call Medical Care! Many are suffering and in the year of 2012 we can do all kinds of miraculous things, but we cannot help our countries ailing health? It is time we do what is right, making money isn't the only thing that you should be concerned of, evenutally you will be faced on the otherside of your own guidelines and you will be treated just the same as I, and others.
My health problems began when I was a child, we excused the difficulty for diagnoses with the time, then early 80's, but now what is the excuse? Have we really learned nothing? There truly is more questions then answers and that is part of the problem. Close to 30 years later, lots of neglect and insults by a medical community that preferred insulting a patient rather than taking responsibility ..left me broke, without a freedom to choose the life I want because of the disease that was left unattended to wreak havoc within me. I wish I could forget this one moment, but for some reason it is the one memory that has stuck. It was a mental pain, rather than my now daily physical pain.

I was a smart student, I struggled, but worked so very hard with my studies to succeed. One day I sat in my advanced algebra math class and stared blankly at my test ...fully knowing I CAN do this, but feeling as if someone just erased my brain clean ...like chalk on a chalk board wiped away. That day marked my first failed math test and many other until I gave up and quit school. Why might you say, well because NO one cared, doctors didn't care, and our friends and family Respect the doctors word and so then they began to not care as much either. I was left lost, just a teen left lost and confused and basically blamed for what was happening as if I suddenly became a Liar overnight?

It took another year before I was diagnosed with Lyme Disease, finally a answer, I thought! Now next is the cure, YAY! I will overcome this, but sadly that didn't happen ...things got worse; the worse my health got, the more I felt rejected by medical doctors I was taught to trust and respect. I know life isn't always fair, but please understand what your ignorance and greed is doing to the lives of so many. I don't care if you call it by some other name or disease, I don't care if you manufactured it or not at this point in my life ...all I want is insurance coverage and a oppurtunity for the choice in my own medical care, with the doc of our choice who can give me treatment choices that I can accept or choose not too. I want my rights back atleast, cause I don't think you can give me back my health or the years stolen from me, from my family, my husband and son. I just want the freedom we claim America stands for. For my son not to endure what I have endured in my time and for us to stand up and make our wrongs right. Will you do that IDSA, will you make your wrongs, right?

Change the guildelines, enforce insurance companies to cover patients who PAY for insurance to help them when they medically need it. It never is to late to make those changes, even if my time is too late ...there is still the future of my son's time. This is just a tad of what my experiences have been like dealing with healthcare. What I'd like is to see ackowledgement, respect, and for those guidelines to change for the betterment of the Americans you have sworn to treat with dignity. ♥ Thank You.

Kimberly Boozer I just want Lyme to be recognized as a serious disabling disease and for Dr's not to belittle me into thinking ONE pill would work against a disease that has ravaged my body now for 10 plus years (before they gave me the pill and I had to go to 6 different Dr's before they even tested me, which they should have done in the beginning)!!! I still have all of the same symptoms and they are worse now....yet I cannot get treatment? Not fair, that I and others have to suffer, including many children, its ridiculous.

Sarah Chappell *My twin sister has Lyme disease. I have watched her deteriorate over the years and become a shell of a human being. IDSA not only needs to recognize the seriousness of this epidemic, but you need to 1) properly educate PHYSICIANS on this disease, 2) educate the PUBLIC on preventing contraction of this disease, and 3) educate INSURANCE companies so that ALL treatments for this disease can be affordable to everyone.*

Diane J. Marie It's hideous that the IDSA would ask, "What would you like to see from your society in the coming year?" THE IDSA MUST STOP DELIBERATELY DISABLING AND KILLING CHILDREN AND ADULTS WITH LYME DISEASE. NOW. Treatment exists to greatly help us--when we get appropriate treatment in time, using the ILADS way. Why does the IDSA prevent us from getting treatment that is appropriate--using the ILADS way? ANswe: The IDSA is an evil medical society that exists for one reason: profits. Profits before patients.

You've allowed Lyme disease to spread worldwide and have hidden this rampant epidemic. Chronic Lyme disease caused progresive MS in me--but it was caused by Lyme disease. Getting great ILADS (www.ilads.org) treatment stopped the MS process. But due to MS damage done, I remain on Social Security Disability. All because the IDSA and infectious disease doctors across the US want us to get expensive drugs we don't need, instead of high dose, very prolonged antibiotics which is what saves our lives and prevents further disability. There is little profit in antibiotics.

The IDSA is guilty of "conflicts of interest," as was found by Connecticut Attorney General Blumenthal (now a US senator: http://www.ct.gov/ag/cwp/view.asp?A=2795&Q=414284)
May the IDSA Lyme guidelines panel members be thrown in prison where they belong. Lyme patients are not going away, we're only getting louder and growing in number as more of us become disabled by chronic Lyme. You can't hide forever.

Jamie GetemBoy Please do something about your lyme guidelines and see that it's not just lyme but also the co infections now that come with it along with parasites. Maybe lyme by itself is not so bad but it's when the diagnosis is missed early and you add the co-infections in the mix it's debilitating. Then we can't get the financial help we need from Social Security, even though out of work for over a year because of the guidelines saying it can be treated.

My husband had worked everyday since he was 15 and can't get his own money so we can pay our bills and for his treatment because of the way your guidelines make it to be no big deal. It is, he is 31 years old walking with a cane do to poor testing and lack of intelligence in the medical community, even the doctors who do know about it won't touch anyone with a 10 foot pole who have lyme or co infections because they are scared to death the will have their license suspended. There is no one cure all for everyone but if you could at least respect how debilitating this is so we can get the monetary help we need, we would have less stress and in turn heal faster. Please consider this as a whole picture of lyme and the immune dysfunction it can cause when other factors are involved. Also let the lyme dx be made on a clinical level not 1-2 stage blood test that are not accurate. If my husband could have been treated on his primary's clinical dx a lone he would have never been out of work and now in the state he is where he is no where near going back to work due to lack of treatment. Thanks for taking the time to read this.

Deb Compton-Venezia By the way later in my 20's I did fight through the confusion and fog of what I endured in highschool and I got my GED in my later 20's after my son was born. I passed first time and was very proud I achieved that. If only my health didn't get much worse, maybe if only the suffering Lyme was causing my was bring treated properly, just maybe I could of continued my life with further schooling and a career. Now my if only.... goals are simple. I just want to cook, clean and take a shower without feeling like I am going to die. Amazing how our perspective and dreams change when we are suffering.

Stephanie Vandagriff Let me remind everybody not to swear or threaten in anyway, so they can't have an excuse to delete our posts. Let's make it when they delete us, it's because they're censoring us and don't want us to be heard. Keep posting people!

Sarah Chappell My twin sister has Lyme disease. I have watched her deteriorate over the years and become a shell of a human being. IDSA not only needs to recognize the seriousness of this epidemic, but you need to 1) properly educate PHYSICIANS on this disease, 2) educate the PUBLIC on preventing contraction of this disease, and 3) educate INSURANCE companies so that ALL treatments for this disease can be affordable to everyone.

Marys Rainbow I would like to see you acknowledge LYME DISEASE and start the process of helping those canadians who are affected!!!!!!!

Shelly Ogline Dehoff Please add me to the list from southeastern PA who want to see Lyme disease and tick-borne co-infections recognized and respected, and treated appropriately!

Neil Huey To Sarah...FACT...The CDC is aware of the epidemic, some say pandemic nature of tick-borne disease in this country. Put pressure on your state's department of health if you want action.

Morgan Zazow Look into the politics of the members who say there is only such a thing as acute lyme disease, and not chronic lyme disease. Play devil's advocate-- hear all sides of the story and look at all the research and all of the information. Then do the right thing.

Heather MacEachern-Tarasick I as well would like to see you acknowledge LYME DISEASE and start the process of helping Canadians who are affected!!!!!! This disease is destroying lives!

Boris B Houndleroy Please help to save my daughter from Lyme disease rather than fighting against those who are trying to save her

Kenneth Damsell live up to there oath and not meny from insurance co to turn there back on sick people

Jen Jasper Wow, people have a lot to say about Lyme disease. I do, too, but I have other things I want to ask about:

Tens of thousands of people lose limbs and die in this country every year due to antibiotic resistant infections -- people who may have a chance to live and even avoid the risks of the more hepatotoxic and neurotoxic antibiotics used if we had access to phage therapy. How can we bring phage therapy clinical trials to the US and save people's lives from acute MRSA and other infections? This I think is an issue for everyone in the world.

You have this goal of producing 10 new antibiotics by 2020. Is there any chance one of these antibiotics under development could be used to more effectively treat Lyme disease? Early and late stage? And by that I mean all genospecies, as there is evidence that different strains respond to different antibiotics.

Lori Shaddy I would love to see you admit that Lyme exists and stop threatening doctors who treat patients with Lyme Disease. I would love for each of you to find a loved one or for you to have a tick bite so that you can see what the reality of Lyme Disease is, personally. That would cause you to see clearly, I am certain. I would love for each of you to live "Under Your Skin" rather than say it was a dramatic film. Lyme is affecting people at a faster rate than AIDS. It affects the brain like syphilis, but people are denied treatment. Now, I bet you wish you hadn't asked. We are people. People who want help. We do not want lawsuits or anything more than dignity, respect, and treatment!

Kathy Obal Carlstrom Jen - many strains of lyme and co-infections have become prescription antibiotic resistant. Natural medicines work better in these cases.

Jen Jasper I have been wondering a few things, and would like some answers. Based on something I've read elsewhere, I'm wondering:
If you think autoimmunity plays a role in post-treatment Lyme disease persisting symptoms, why is it that after an analysis of the studies on autoimmunity, there was no relationship to autoimmunity found? To quote an NIH paper:

National Institute of Allergy and Infectious Diseases, NIH: Impact on Global Health (2009) by Vassil St. Georgiev, PhD

Chapter 22.1 Lyme Disease (Lyme Borreliosis, Lyme Arthritis)
Section 22.1.5.4 The Role of Autoimmune Reactivity in Lyme Disease

"In NIAID-supported clinical studies, case subject patients with PTCLD* were compared with control subjects without such symptoms for the presence of several human leukocyte antigen (HLA) class II (DRB1 and DQB1) genetic markers, some of which are known to be associated with the expression of autoimmune reactivity. The results obtained did not support the involvement of an autoimmune mechanism in PTCLD (24). However, because not all autoimmune diseases are associated with specific HLA haplotypes, these findings do not necessarily exclude that possibility. Definitive proof would clearly involve demonstrating the presence of significant levels of relevant autoimmune antibodies and/or autoreactive T cells in patients with PTCLD but not in treated control subjects without such symptoms. A greater frequency of DRB1*0401, which has been reported to be associated with antibiotic-treatment-resistant arthritis, was noted in the case subject patients; although this finding appeared to be nominally significant ($p < 0.05$), its biological significance is ambiguous because none of the case subjects considered had symptoms of inflammatory arthritis.
(http://www3.niaid.nih.gov/research/topics/lyme/research/autoimmune/)"

If HLA-DR4 and other genetic markers are important in determining which patients stand to develop persisting symptoms, I would be making testing for such markers part of your guidelines. I would appreciate it if in the new year you dedicated a portion of your web site to explaining the evidence you have supporting any autoimmune basis for chronic Lyme disease. A lot of patients have never seen a solid explanation for this at all. And quite a number of patients have gotten better whilst on longer-term antibiotics.

Susan Hanson-Haywood PLEASE take Lyme disease more seriously. We are suffering daily in horrific ways and need help!!!!!!!!!!

Courtney Lynn Research,treatments,diagnostic tests,doctors knowledge of the disease and the guidelines are ALL flawed concerning chronic lyme disease. It is time to do the right thing and get these mothers,fathers,sisters,brothers and children the care that they deserve!

Jen Jasper Darn, hit "return" too early. I meant to include more.

I want to know how it is you think Lyme disease/Borreliosis can't persist after antibiotic treatment. I thought that Borrelia has been cultured from ACA skin in Europe a decade after initial infection and treatment? And why can't it have a latent phase? Even one of the test kits for Lyme disease states that latent Lyme disease and seronegative Lyme disease exist, yet in other documentation online your position statement has been that neither occur.

From Zeus Scientific's Athena Multi-Lyte Borrelia VlsE-1/pepC10 Plus Test System package insert:

"Spirochetemia occurs early with wide spread dissemination through tissue and body fluids. Lyme disease occurs in stages, often with intervening latent periods and with different clinical manifestations."

and

"Asymptomatic subclinical infection is possible and infection may not become clinically evident until the later stages."

and

"Patients in early stages of infection may not produce detectable levels of antibody. Also, early antibiotic therapy after EM may diminish or abrogate good antibody response. Some patients may never generate detectable antibody levels. "

Reading this from a professional use insert for a VlsE test widely used by many doctors, one would think that any issues about latency, subclinical infection, and seronegative Lyme disease would not be controversial. Coming from this source and not a controversial LLMD's office, what can you say about this?

Morgan Zazow The "right"decisions to make are obvious enough. 1,438 and we will not stop. Most of us have the time, as we sit or lay because we can't do anything else.

Jen Jasper @Kathy Obal Carlstrom: Please tell me what they are, I'd like to learn more. Thank you.

Wendy Hayward HELP People with LYME disease!!!!!! REGOGNIZE, SUPPORT, HELP get treatment for these these thousands of people who have it so they can LIVE and be alive to help support and help the many of thousands yet to come!!!

Heather Lynn Find and support an accurate test for lyme and vector borne diseases. Eliminate the need for debate with early recongition, ending the suffering.

Lisa Chrismer Hix I would like to see you work together with ILADS and the doctors who are helping those of us with chronic lyme disease. If you don't work together to get the guidelines changed so that we can get insurance to cover proper care we will run out of money before our families are helped.

Please stop and consider that your long standing opinions of lyme disease could be wrong. I believe there are many good and caring doctors who are not helping us because they have been trained to believe the standards you have devised for care.

Athena Kern Please change your guidelines on lyme disease detection and treatment. The doctors who are open-minded and knowledgeable enough to successfully help people have also become infected themselves or who have family afflicted with these severely debilitating and harmful tick-borne illnesses. And they must do so while risking their license because the IDSA refuses to help lyme disease people. That is WRONG. How long did it take for AIDs to be accepted and acknowledged as an infectious disease not just afflicting gay people? How long after that did it take for researchers to actively seek a cure? Is it really necessary to go through all these hoops for every major infectious disease?! When you know infectious disease is killing people, stand up and help, don't make things even harder for those who are sick!

Jen Jasper IDSA, I think you need to do more to reach out to patients and help them in some concrete way. Like more research on treatment and persistent infection and a place where people can regularly ask questions and get a well-reasoned useful and informative answer. An actual dialogue. And how about trying something outside the box? What about clinical trials of rituximab for those with severe fatigue related to chronic Lyme disease? Would you try to see if there's a human model of immunity and genetics which matches Huber's mouse study?

Because if so, you might find that patients suffer from both persistent infection AND a deficient immune system.

I bring all this up for serious consideration. Like many people who have written here before me, I lost my ability to work due to chronic pain and disability after having been bitten by a tick. I was fine before the tick bite. Not so afterwards. I have lost tens of thousands of dollars through medical expenses and medical debt, through trying what LLMDs and non-LLMDs have advised. And I am still ill, when I could be working in the sciences again. I don't care at this point what name you give my condition. I just want more research done and a solution to be found that helps me and everyone here. There has been too much human suffering.

Margaret Melson *I would like to see IDSA recognize lyme as the epidemic it is. I would like you to develop accurate testing and helpful, effective treatments. I would like co-infections to be investigated and accurate and effective treatments developed for them. I would like the IDSA to quit acting like people who have lyme are crazy, depressed, psychosomatic....the lyme spirochete is closely related to syphilus...you believe in treating that, don't you?*

Margaret Melson I would like to see IDSA recognize lyme as the epidemic it is. I would like you to develop accurate testing and helpful, effective treatments. I would like co-infections to be investigated and accurate and effective treatments developed for them. I would like the IDSA to quit acting like people who have lyme are crazy, depressed, psychosomatic....the lyme spirochete is closely related to syphilus...you believe in treating that, don't you?

Denise Weaver Could you please allow all posts to be preserved as opposed to deleting them....TY

Denise Weaver As a lyme patient of ten years, I appreciate seeing others opinions and perhaps someone will be able to help us...thank You

Shira Lee It would be great if Infectious Disease Physicians were more aware of the severity and treatment options for chronic lyme disease and co-infections. Also, that the organization be motivated purely and completely by wanting the well-being and health of all individuals. Thank you for asking!

Bettina Gartlehner Ich habe chronische Lyme-Borreliose und ich finde es schlimm das diese Erkrankung nicht als solche gilt. Ich bekomm schwer eine weitere Behandlung da ich mir keine privaten Ärzte leisten kann. Bin Mutter von 2 Kindern (2und4 Jahre) und mach mir auch Sorgen um ihre Gesundheit da ich nun weiß das ich in der Schwangerschaft schon Borreliose hatte.

Keiner weis etwas und keiner tut was. Wann wird endlich reagiert, die Krankheit ist genau so schlimm wie Aids. Nur wir werden ignoriert. Bitte wann hilft uns wer?????

Michele Wood Haynes It is heartbreaking to read these posts here. So many suffering, so many lost, and all due to a treatable disease. I saw a commercial on tv yesterday celebrating the compassionate treatment of HIV and AIDS. And then we have Lyme disease, the forbidden disease of the 21st Century that is treatable with inexpensive antibiotics in most cases, and long-term IV and/or oral antibiotics in late stage cases. Time to wake up and revoke your treatment guidelines.

Susanne Engelhardt Be aware! We need help!

Ruth Thomas We need the IDSA to update its doctors in Lyme awareness, to recognize the legitimacy of LLMDs, to withdraw the ineffective two tiered ELISA and Western Blot, to accept IGenix tests as valid, and a clear and widespread understanding that Chronic Lyme exists and needs longterm treatment. I lost 2 years of my life due to IDSA doctor ignorance of Lyme realities. With 4 months of recent antibiotic treatment, I am finally well, thanks to a NON-IDSA doctor. If you want to help, you need to embrace new findings and CHANGE current beliefs. Thank you. (Please don't delete my post again.)

Christine Heidt I wish the IDSA would heed the warnings of their own researchers, Khan et al, of the IDSA who revealed that over 50% of the IDSA's guideline recommendations are not based on science but rather are based on "expert opinion". Furthermore "bias" was indicated as being problematic during the formation of many IDSA recommendations and appears to be the case again with Lyme disease.
I wish the IDSA would work in harmony with the Lyme community rather than wasting precious time debating and denying research that deviates from their researchers "expert opinion".

I wish the IDSA could open their minds to the fact that researchers other than those from the IDSA have valuable knowledge to bring to the table. After browsing through the reference section of the Lyme disease Guidelines it becomes apparent the IDSA considers itself to be the only source of accurate information even though it is often based on "expert opinion" rather than hard, cold facts.

The Lyme disease dilemma is not going to end until further research and clinical trials reveal the truth. Put your money where your mouth is and prove that your "expert opinion" is valid, or maybe discover that it is not correct…but do it in an unbiased setting please.

Julianne Zhou Please hear what we are saying.
Your society's beliefs on Lyme treatment and diagnosis stand in stark contrast to the personal experience of thousands.

Joan Lulich I have lyme free because of energy work, NMT and Yuen Method. Before energy work, I found high doses of iodine helped me become more functional.

Karen Miller Since you ask, I want you, IDSA, to revoke your guidelines. Doctors in my part of the world look to CDC for information on diseases, they see your guidelines, and from then on are so misinformed that they are a danger to their patients. My primary care physician said that nothing will change until those guidelines are changed. You have a responsibility to the public. Please act in OUR best interest and revoke your guidelines immediately.

Jeff Hickson You are the abomination in the medical world. Denying for years the existence of a disease that has now effected 100s of thousands.Chronic Lyme. I was left untreated for more than a decade in a state that adopted IDSA protocols. I became paralyzed, cognition problems, memory loss, speech impediments, constant pain and all because as a group you denied the existence and limited the testing and diagnosis guidelines for Chronic Lyme disease. I had a disease that did not exist and was thus given multiple other diagnoses that would never give me actual relief. I was told that I would never get better. It was all in my head and so much more. It was not until I got myself out of MA and into CT and treated by an ILADS trained MD who feared for the loss of his license that I actually improved. ILADS saved my life. My LLMD saved my life. My persistence to go beyond the garbage that you spew saved my life.

Jeff Hickson What do I want from you? I want you to go away and be replaced with Drs who care more about their patients than their academic credentials. Cannot change your mind as you would admit to being wrong. Accept your mistakes and start helping patients or go away!

Karen Miller The previous comment was about Lyme Disease, written by a very fatigued patient. This is what our life is like! (ex-structural engineer, now on disability and fighting for treatment of lyme and several other tick-borne diseases.

Chispa Loro I would like to see you revise your Lyme disease criteria, including recognition of the chronic phase of Borrelia burgdorfii. I want you to alter your statement about Lyme and include definition, diagnosis, and treatment guidelines that are in line with science and what ILADS and Dr. Burrascano have published and made available.

Kathy Sprye Goebel A cure and NO PAIN

Kathy Sprye Goebel and a way to pay for treatment to be rid of this CHRONIC LYMES

Lynne Dee Light Barrett I would like to see hard work to create HONEST tickborne guidelines that don't leave OUT those of us who have been ill for so many years with chronic illness.

I would like to see a demand from your members to stop the politics, and money politics so that our young people and children do NOT have to live a LIFE filled with pain and chronic illness which robs them of a life worth living.

Waking up daily with only pain and unbearable symptoms --which the IDSA states are all in my mind makes me that much worse. 19 years of suffering the devastating effects of Lyme and Babesia have taken all of my adult life away from me. I suffered many years prior to that, but no one even tried to help me as I grew up in pain and weakness. I wasn't diagnosed until 2000 after suffering throughout my life. I DO NOT want to see this happen to the children of today! I do not want young people suffering and losing their lives to these diseases. Even if we live through

Lynne Dee Light Barrett Lyme Disease, the quality of life is so slim that it rarely makes life worth living.... SAVE our CHILDREN and the rest of us who have suffered lives of devastion from Lyme Disease. Change the Guidelines and HELP the hundreds of thousands who ARE trying to LIVE their lives with some bit of normalcy. STOP the lies and politics and Help those who are suffering ever lasting pain and ruined lives due to Chronic Lyme and other forms of this disease! Lynne Barrett

Kimo Bailey Ditto.

Patti Cridge Benalayat I continue to ask the IDSA to change their Lyme guidelines. Their current guidelines have caused many patients to remain sick and get sicker. They have caused patients to pay for many treatments out of their own pockets, because insurance companies won't pay for the necessary treatments based on IDSA guidelines. This disease changes families lives for the worse. Please reexamine your guidelines and reach out to those of us who are suffering.

Stephanie Hart the lies about Lyme Disease to be retracted !!! and a few apologies for the cover up !!

Kelly Mairson I was deleted once before. It feels a bit like how I was treated by Dr's before I found my ridiculously brilliant LLMD :-)

That being said, I really have nothing new to share except hoping you can teach your Dr's to listen to their patients. I am posting some comments made to me by Dr's who followed YOUR guidelines when I first got sick-

"You really should consider starting a gratitude journal and writing down the things you are thankful for because you look pretty healthy to me"

"Everybody gets tired. I'm tired right now"

"You women, you always find something wrong. It's probably RA and there is treatment for that"

"Coinfections? You only need to worry about them if you are elderly"
"Enjoy your vacation, there is no Lyme disease in Maine"

"You don't have those symptoms. Your knee is not swollen"

"Maybe your shoulder hurts because your purse is too heavy. Or maybe it's from pulling wet clothes out of the wash"

"I think you should talk to someone. I know it can be difficult getting older"

"People with Lyme infections don't look like you"

Doesn't that make you proud? It took me 16 months to get diagnosed because of the nonsense above. If they had just listened to me maybe it wouldn't have taken so long. I am so incredibly thankful for ILADS and the Dr's who treat us :-)

I wish so badly your organization would learn something from them so others don't go through what I did :-(

Katherine A. Doherty-Peterson I'm new to Lyme disease.... but that doesn't mean I just got it... I have had it for years and the doctors skirted around it year after year.... finally after firing several doctors my ND knew right away what it was.... I've heard much of the same things Kelly has... 'It's all in your head" and so forth... a doc spends 10 minutes with you and brushes you off... but their not wanting to take the time is playing with, not only the quality of my life going forward, but my life in general... it's sad that people are not educated about Lyme and just think it's like the flu... Education is the best weapon ...

Gayle Link IDSA. I am one of the lucky ones. I was a chronic lyme patient who got my life back because of a compassionate LLMD (Lyme-literate Medical Doctor). He was willing to put his license on the line for long-term antibiotic and holistic treatment for my lyme, babesia and bartonella diagnosis. I ask you to read each of the almost 1,500 responses with an open mind. These are real people. This is a real disease. Many of them feel life isn't worth living through the pain (and many have died because of it). Your guidelines do not work, are not effective and do not address that it is a chronic illness when not treated correctly in the acute phase. We know you care. You are human beings. Please show it by responding and letting us know how you plan to make a change.

Christian Dreibrodt Please help the people. Your guidelines are the reason that many people become chronic lyme disease.

Stephanie Vandagriff My Lyme people, keep contacting media outlets. We need to get heard!

Logan McCulloch I'd like to see Lyme literate MD's included in the standards review process, and restrictions on the % of research articles cited which are authored by the members of the review boards themselves. I'd like to see formal input by the patient community.

Peninah Ann Fairness. The willingness to save the lives of millions of people who suffer from tick-borne diseases. Because of your guidelines, the docs refused to treat my kids and two have brain damage from neuroborreliosis and bartonellosis. I have seen people die because of your decisions.

Peninah Ann I took a man to the ER who had chest pain. I told them that he had babesia. They did not help him, although he was in critical condition, they sent him home without rehydration, or any effort to save his life. No doctor in the ER knew how to take care of him. Can you explain why?

Peninah Ann My husband was life fighted 2 times, and hospitalized 5 times. When they gave him antibiotics, he started to recover. When they took them away, he lost function. They never checked him for bartonella and borrelia, even though our whole family is infected. the IDSA doctor refused to test him for lyme disease. When asked, he said "no", turned around, refused to speak to either of us, and immediately discharged him, although he was critically ill.

Peninah Ann By the way, my husband died without treatment because of your teaching and guidelines. He was not very old.

Peninah Ann Also, I want to say, that the numbers are on our side. In four years of talking with people in our state, 7 out of 10 people know someone with Lyme disease. But of course, there is no epidemic of Lyme disease. amazing that people off the street know more than the experts, by spending talking to people in the community.

Lisa Castillo I am a chronic Lyme sufferer of almost a decade. As a result of the ignorance and dispute in the medical community there are thousands of us suffering beyond comprehension! I am beyond frustrated with what is available to those of trying to conquer this insidious disease...if you don't have financial means you are screwed since insurance basically doesn't cover the costs to overcome the chronic condition of Lyme. My ask is that someone out there actually will develop some sort of support and solution to the most under diagnosed disease effecting Americans and people all around the world. Thank you

Debby Matthews It would be nice to hear from the one manning the delete button!!!! Can we get some answers to the questions...Why so silent?...Hellllooooooo!!!!!!! Not real professional!!!!!

Shalome Sine Are you seriously asking this question? Those of us who are suffering from Lyme's disease know what we want this year. Proper research into Lyme's.

Peninah Ann I hear they have deleted hundreds of comments already, LOL.

Michael Brookins Come up with a CURE for LYME...This is REAL and these a real people that are suffering....and hurting....and unless you have LYME or has a love one that has it...it appears no one cares....WAKE UP America...WE need your HELP!!!NOW.......

Sara Connor To the IDSA
Please explain to me the treatment for Whipple"s Disease.
Whipple's Disease is a bacterial infection.
Lyme Disease is a bacterial infection.
Whipple's Disease relapses !
Lyme Disease Relapses !
I am willing to learn something from the IDSA !
Please help me understand the difference between the bacteria.

If the IDSA dosen't believe in long term treatment.
Why treat long term for Whipple's Disease ?
and not treat Lyme Disease for long term ?

Treatment for standard cases of Whipple's Disease from the Mayo Clinic's web site.

In most cases, Whipple's disease therapy begins with 14 days of intravenous (IV) ceftriaxone (Rocephin). Following that initial therapy, you'll likely take an oral course of trimethoprim-sulfamethoxazole, or TMP-SMX, (Bactrim, Septra), for one to two years. A shorter duration of antibiotic treatment may lead to a relapse. Another common treatment begins with 14 days of IV infusions of streptomycin and penicillin G, followed by oral TMP-SMX for one to two years.

Treatment for severe cases
If you have neurologic symptoms, you may be started immediately on a 12- to 18-month course of oral doxycycline (Vibramycin) combined with the antimalarial drug hydroxychloroquine (Plaquenil). You'll also be given long-term antibiotics that can enter the cerebrospinal fluid and brain, such as TMP-SMX.

I DON"T GET IT !

Allison Nevitt Please remove and prosecute anyone who has been on any panel setting Lyme guidelines with a conflict of interest.

Then, please, revisit your guidelines by considering all the clinical and research evidence out there. Not what is filtered.

Please let the world know the severity of the epidemic. Please validate people with chronic symptoms to due Lyme disease and attendant diseases and disorders - such as auto-immune deficiencies.

Please stop consulting to insurance companies and giving them validation for denying claims for tests and treatments.

Allison Nevitt Last thing, please accept responsibility for all those who have suffered and/or died due to your "guidelines" which are used as bully sticks to create de facto law.

Thank you and may this be a compassionate year.

Janet Laidlaw Recognition, support and help for Lyme Disease.

Misty StopMonsanto Sparkman Someone fill me in, what is goin on with Lyme disease? Confused. Sounds like it is a big problem. Are more people getting it?

Jen Jasper @Misty -- A lot of people who were not diagnosed with Lyme disease shortly after a tickbite or misdiagnosed have been very ill for a long time and have found that, in their experience, taking the amount of antibiotics recommended by the IDSA is inadequate for recovery. Insurance companies will not pay for additional treatment. The IDSA has stated that Lyme disease cannot be a chronic and persisting infection, and any antibiotics beyond the amount mentioned in the guidelines is unnecessary. The IDSA has speculated that persisting symptoms after antibiotic treatment are caused by an autoimmune disorder. The research for this is not definitive. More research is needed, and those of us put in the position of having to figure out just how to treat this condition are not getting enough research.

Jen Jasper I should add here I'm somewhat different in this regard. I know I was bitten by a tick early on and had an EM rash -- both case definition criteria that should have led to treatment asap rather than getting it nearly 2 months later. There must be a gap in physician training, as my doctor told me there was no Lyme disease in California -- yet the area I was bitten in had been flagged by Dr. Robert Lane's department from UC Berkeley (he studies ticks and worked with Burgdorfer himself). The state and the CDC know that N California is endemic. The doctor should have known too.

Jen Jasper *I should add here I'm somewhat different in this regard. I know I was bitten by a tick early on and had an EM rash -- both case definition criteria that should have led to treatment asap rather than getting it nearly 2 months later. There must be a gap in physician training, as my doctor told me there was no Lyme disease in California -- yet the area I was bitten in had been flagged by Dr. Robert Lane's department from UC Berkeley (he studies ticks and worked with Burgdorfer himself). The state and the CDC know that N California is endemic. The doctor should have known too.*

I had to go to an LLMD to initially get treatment for something that was obvious. It could have been entirely avoided. I have ended up with persisting symptoms, and regardless of the cause, I want more research and compassion for dealing with this. And at the very least, if I am sick, more acknowledgment for persisting symptoms to be an officially recognised condition. Is there an ICD code for post-treatment Lyme disease? I don't know. I know there is one for Lyme disease and my GP has used it in referrals to specialists - even though in theory I should not have it any more. Isn't that interesting?

Kyle Rider To touch base with the above comment concerning Whipple's disease. The following link are the treatment guidelines and so forth. Really blows a hole in the IDSA guidelines against using longterm antibiotic use for the treatment of Lyme.

Shelly Hebert I was told by one of many doctors to drink a 5 Hour Energy Drink and go for a massage to treat my joint pains and fatigue. I guess the almost 1500 people that have posted on here need to do the same thing.

Jennifer McNeill Wallace I am just one of many Holly Springs, NC residents afflicted with Lyme disease and coinfections and the numbers are growing here daily. Our stories are all the same. We are husbands, wives, sons, daughters, fathers, mothers, teachers, businessmen, doctors, nurses, students who did not deserve this. We were leading productive, wonderful lives full of health and happiness when we became ill out of the blue.

We listened to all the doctors who said “there is no Lyme in North Carolina,” “you are just stressed,” “you need to see a psychiatrist,” “don’t ask me about Lyme disease again,” “you have Chronic Fatigue syndrome,” “you are not weak,” “you are not sick, your labs look perfect.” You cannot call yourself a doctor if you are not listening to all of us begging to be helped.

We are made to pay tens of thousands of dollars to recover our health all because of your flawed treatment guidelines. I became ill with a 2 year old and 4 year old that needed their mother. I am finally doing much better now thanks to 10 months of IV antibiotics and continuing oral antibiotics and no thanks to you, but rather to my Lyme Literate Medical Doctor who happens to be a brilliant infectious diseases specialist whom I can call a real doctor. He has integrity, is brave and, above all else, cares about his patients, so much so, he gave up everything to continue to fight on behalf of the sick. He is saving my life and you are not.
I still fight daily because of the untimely manner of diagnosis due to the faulty blood tests, but I continue to battle because I deserve to live a life full of health and happiness again. You are taking mothers and fathers away from children, destroying childhoods, ruining lives, dividing families, and subjecting people to unimaginable suffering. Why are you doing this to your patients? Why are you not TRYING? Where is the research? Why are you ignoring us?

These are the questions I would like “our” Infectious Diseases Society of America to be answering in the year 2012. Update the Lyme disease guidelines so insurance companies will pay for treatment and doctors can help their patients without fear of losing their licenses, develop superior testing, and listen to and integrate the research that is being done outside of your society. Please help us for a change. We do have brilliant minds and can assist you in this quest. Listen to us. This could be a huge step in the right direction. Thank you so much for asking, Jennifer Wallace, wife and mother of 2 little boys (pictured above - all they want in life is for Mommy to get better), Holly Springs, NC

Susan Larsen I'd like to also see the ISDA guidelines appropriately updated regarding congential lyme. Lyme can be transmitted to babies and our children need to be appropriately tested and treated. We are creating a generation of undiagnosed lyme that was not transmitted by the bite of a tick.

Sarah Elizabeth Shipman I would like more realistic guidelines written by doctors who treat Lyme on a daily basis and can give a more accurate timeline on treatment. Then my insurance would actually pay for something!

Paula Gallo Misty OccupyEverywhere Sparkman: Please see the film "Under Our Skin" and you will get the big picture. Lyme disease is growing faster than AIDS. or go to ILADS.org

Kyle Rider Highlight the treatment section to the above one year. If you gave treatment to a newly diagnosed Lyme Disease patient caught in early stages for one year. Maybe you would have less people collecting disability and medicare. One thing that is almost certain is you would have a lot less people suffering for over 20 years with this horrendous disease. WAKE UP!

Sandeep Gopal IDSA sucks!! Keep the right doctors in the lyme board. How many of your doctors have financial interest in pharma and insurance?

Deanna Wood 1,500 comments and counting. I'd say the message is clear. Recognize chronic Lyme as the travesty it is!

Kim DeSantis Goodwin As my family suffers i wonder how my daughter got daily bactrim as preventaive for the past 2 years because she has urine reflux so just in case she gets an infection uti then the medicine prevents it. 2 years on antibiotics for something just in case. My son when he was 3 was put on antibiotics for a full year as maintenace not to get another ear infection. Why for these minor things that have no bacteria and easy to treat if there is a bacteria growth but not for this? This bacteria is the devil man made changed from the original bacteria back in europe so many years ago. We all know that plum island released these man made ticks from the Nazi scientist Traub. This was meant as a bio weapon and you all know that. This whole thing is so corrupt and that is why it is such a big goverment secret. Its time to change

Kim DeSantis Goodwin
http://www.rense.com/general67/plumislandlyme.htm
Expand Preview

Kim DeSantis Goodwin
http://daniellealbert.blogspot.com/2010/10/lyme-disease-result-of-us-biological.htmlExpand Preview

Jesse Lee Hughes I am slowly & painfully dying because of your stupid guidelines on Lyme. Please stop denying the truth. Too many are suffering. Do whats right.

Sonya Nelson After losing everything to Lyme Disease, becoming fully disabled, I would like to see better testing and TRUE research. Don't stop until you have the REAL answers. Dependable testing!

Just admit you don't have all the answers so people like me can get coverage from our insurance companies.
2 ½ years of IV antibiotics along with IM injections, oral antibiotic, traveling to see doctors that are willing to go against the IDSA, thousands and thousands of dollars (with good insurance), and I am improving. I feel as though I am finally getting my life back.

Kris Thecanary SisterLyme Open your eyes to our pain, sickness that is NOT IN OUR HEADS. Look into our Lyme disease full force. Don't be SCARED of it. We would appreciate the same dignity that you would give any other patient with an "infectious deisease" We don't need to be treated like you would treat a dog. That's happened WAY too many times.

Francine Monroy The education of ALL physicians not only Infectious Disease in the state of Florida regarding Lyme Disease. Maybe my daughter, who now has neuro-borreliosis would have had a chance of some normalacy since the age of 15 if physicians would have opened their minds and not laughed at me for telling them it was not Fibromyalgia, Chronic Fatigue Syndrome,Insomnia,Arthritis,Tachycardia etc. My heart is breaking for my 23 yr old...........

Georgia Stamos I would like to be treated like a human being. I do not wish for anyone else to go through years of misdiagnosis like I and many others have due to your guidelines. These tick-borne infections need to be treated appropriately and in a timely manner before damage is done. Lyme Disease is a chronic infection and long term antibiotics helped me get to a place I thought I would never see again even though the years of misdiagnosis has caused permanent damage. We need more research and a cure, don't let this happen to more people-change the guidelines.

Donna Riley Michaud to listen to those who are living the life of "Chronic" Lyme Disease, which is said not to exisit, whatever it is then, to find a cure and come to a general understanding so that I do not have to see my 6 year old child deteriate before my eyes..

Carl Tuttle Please read this letter and click on the “agenda” link to see what took place on Aug 18th at the NH Department of Health

Aug 22, 2011
Office of the Governor
State House
107 North Main Street
Concord, NH 03301

Dear Governor Lynch,
A two year effort to alert our public health officials regarding faulty Lyme diagnostic tests continued with a meeting held at the New Hampshire Department of Health and Human Services on Thursday Aug 18, 2011 at 1:00PM

Although Director, Dr Jose Montero wasn’t present four other public health officials did attend. We had seven clinicians, two state representatives, and an independent filmmaker in attendance.

The focus of the meeting was to educate our health officials regarding the rampant misdiagnosis of Lyme disease due to the faulty Elisa and misleading commercial Western blot. Misinterpretation of laboratory results is the main reason why the medical community is dismissive of Lyme patients and their symptoms.

A prepared agenda with proposed resolution was distributed to all attendees and followed closely. We were given an hour to present and everyone had an opportunity to speak who wished to do so.

Nashua Pediatrician Dr Emory Kaplan who has been unable to practice medicine for the past three years due to Lyme disease read his prepared statement in front of his colleagues who work for the Department of Health. His Elisa and Western blot were both negative.

Near the conclusion of the meeting State Representative John Cebrowski had strict words for the members of the Department of Health and said, “Doing nothing would be seen as negligent”

The Department of Health has promised to present the material to Dr Jose Montero and get back to us in two weeks. The consensus among those in attendance was that we intend to hold their feet to the fire.
http://home.comcast.net/~runagain/Dept%20of%Health%20Agenda.pdf
Sincerely,

Carl Tuttle
Hudson, NH 03051

Hayley Singleton Be compassionate and change the guidelines for Lyme Disease. Many of us are needlessly suffering.

Valerie Mains Wolfer So many posts have been deleted. I am sure they have a legal team continuously monitoring and deleting the most incriminating posts.

Sherrill Franklin The Lyme and tick-borne disease epidemic won't be the last "emerging infection" challenge we'll face in the coming years. With that in mind, perhaps it is time for the IDSA to rethink its guidelines. Adopting the veterinary community's spirit of inquiry when it comes to tick-borne illness wouldn't be a bad place to start.

Catherine Price Educate ALL healthcare providers about practicing ILADS guidelines and not IDSA guidelines because they are in fear of losing their licenses if they practice ILADS. Educate and Eradicate Lyme/Co-Existing infections...Please!!!

Jen Violet Lyme Disease!!

Kathe Gerhardt I would hope that the sheer volume of requests to have the "medical world" acknowledge the existence and provide doctors with viable treatment options and require insurance companies to recognize the claims would be more than enough to shame you into actually following through. So many victims suffer needlessly because chronic Lyme disease allegedly does NOT exist...HELLO...IT DOES!

Tammy Betterton insurance coverage for decent Lyme disease treatment.

Patsy Swinson Every Lyme patient that dies because of your refusal to acknowledge it is blood on your hands.

Chris Morbelli-Urbanowski Plum Island

Chris Morbelli-Urbanowski You don't have to admit anything, just do the right thing NOW!

Mabel Quinones I guess hitting the delete button is the IDSA's answer to our comments. Why am I not surprised.

Nancy Genova *I have tested positive for Lyme since 2006...deteriorated a year later and was told 'You Cannot Get Lyme Twice'....felt rejected by ID specialist who wanted to pull my picc after 21 days...my story is similar to all posting hear. But we are told (til we find an LLMD) that we are literally crazy, suffer from hypochondria etc...while our families watch us DIE! I still test positive on bands that prove ACTIVE infection as well as a nice co infection of babesia!*

Donna Lewis Better testing (more conclusive) for Lyme-- so doctor's can quit saying "we don't have Lyme in this area"...

Sherrill Franklin Accurate doctor's office tests for Lyme and the gamut of co-infections would go far to eliminate needless suffering. The gross inaccuracy of existing tests is at the heart of patient difficulty when it comes to proper care and treatment.

Chris Morbelli-Urbanowski Perhaps educate doctors to take Lyme disease as seriously as my veterinarian does.

Phoebe Klemz a clean blood supply for future transfusions, free from Lyme disease and the many co-infections that you don't test for.

Sue Larkin Duckworth 1. I would lke the responsible members of the IDSA to issue an apology to their organization and to all Lyme patients and physicians for the appalling behavior exhibited throughout the mandated Lyme disease Antitrust guidelines review debacle. Every aspect of it showed disrespect for the panel, the truth, patients, and the medical profession. Other members of the IDSA should be ashamed to have these 'medical professionals' in this organization, let alone be in positions of authority.

2. Acknowledge that Chronic Lyme exists; screening patients with the ELISA test that IDSA Lyme experts knew had poor sensitivity (as low as 50%!), THOUSANDS of patients with Lyme received false negative results by doctors taught by the IDSA that this definitely ruled out Lyme. With a spirochete infestation in their bodies, untreated, for months to years until finally diagnosed by further testing, how can one deny to these patients that their now "chronic Lyme" does not exist? What else do you call it, doctors? As a Clinical Lab Scientist, I was shocked to learn that a test with such poor sensitivity was being used at all, let alone be used as the sole determinant of negative for undeserved patients, including my daughter, whose childhood was ruined by undiagnosed Lyme. When HIV

screens first came out, anything under 90% sensitivity was unacceptable. And improvements came quickly on test kits.

But why not the same concern for Lyme patients? How could such a cruelty be allowed to devastate so many people? Why not make this critical information more clear to physicians, so they could diagnose on symptoms as was actually recommended by the FDA so patients wouldn't go untreated as they do now? How can this organization not fully grasp this grave situation and put an end to it?

3. Members of the IDSA must clean house and restore its reputation. Certainly there must be members who are disgusted by the behavior of this IDSA old guard, who are desperately trying to save their reputations at everyone else's expense. There is just too much evidence and too many people harmed to ignore this.

Threasa Bryant ONE WORD "HONESTY!!!!!!!!!!!!!!!!!!!!!!!!!!"

Brenda Smith Smart More research on a cure for Lyme Disease and help for people living with Lyme disease.

Mitch Gordon I recognize that this is a FaceBook page intended for medical professionals who belong to the society. To those of you reading these postings who are medical professionals, I'd like to ask you to do three things: 1) read through a lot of these posts and take some of these personal stories to heart, so that you get a sense of the extent of the neglect and harm the Lyme patient population is experiencing, 2) read Dr. Burrascano's 2005 Lyme guidelines (http://www.ilads.org/files/burrascano_0905.pdf), to learn the essential points of what an expert clinician in chronic Lyme treatment with a long track record of success understands about the diagnosis and treatment of Lyme and coinfections, and 3) start reviewing the research of Dr. Sapi's team at the University of New Haven and presentations at ILADS conferences (www.ilads.org). We in the Lyme patient community so badly need the mainstream medical community to dramatically change course on this disease.

Paula Gallo How about you support a protocol that is cost effective and works, IV vitamin C therapy for Lyme?

Karen Smith Research into correct diagnosis and treatment of Lyme disease..... For a skin bacterial infection such as acne - 6 months to two years of doxycycline can be prescribed - and yet for Lyme disease - which is a bacterial infection that may infect every organ of the body - including the brain..... Only three-four weeks of anti-biotics is allowed??? There are far too many treatment failures and chronically ill people with the current guidelines..... Research and doctors looking critically at the current guidelines is urgently needed...

Jim Vetter Please start taking Lyme Disease seriously and prevent the suffering and loss of so many and help those already suffering.

Rob Labicane Help cure Lyme for our friends and family who suffer and update your treatment guidelines so that insurance companies will pay for treatment for my friend who suffers from Lyme disease.

Caity Boyd this is so funny. for a disease that doesn't exist, a whole lot of people are suffering from it..are we all just "imagining" symptoms?

Peninah Ann To ask Children's Mercy in Kansas City to please test and treat children. They are dying to be "seen" by physicians that are trained to take care of bacterial infections instead of making fun and mocking the children's parents. I followed a young girl to the hospital and her parent had to accept steroids as part of the treatment (which is contraindicated in the treatment of autoimmune disorders and suppressed immune system--conditions found in patients with Lyme disease). The doctors refused to accept that she had Lyme disease and treated her for something else.

Peninah Ann To ask the Veteran's Administration to read a simple pamphlet about the existence of Lyme disease. They were determined to let me die rather than accept my diagnosis and provide an antibiotic. They told me that tick borne diseases do not exist.

Nancy Genova I have tested positive for Lyme since 2006...deteriorated a year later and was told 'You Cannot Get Lyme Twice'....felt rejected by ID specialist who wanted to pull my picc after 21 days...my story is similar to all posting hear. But we are told (til we find an LLMD) that we are literally crazy, suffer from hypochondria etc...while our families watch us DIE! I still test positive on bands that prove ACTIVE infection as well as a nice co infection of babesia!

Peninah Ann To ask Wolfram Zuchert, Phd, to quit teaching medical students at Kansas University that its okay to treat people with an antibiotic if they have late stage symptoms of Lyme disease like bells palsy, "but only in endemic areas!" What kind of advice to physicians is that? To only allow treatment if your county has an "endemic" status when it is obvious that a late stage neurological symptom common to Lyme disease is present. When he came to Ottawa to teach physicians from the surrounding towns, they were told, "Lyme disease is not a problem in Kansas." However, ten business owners and their family members were infected and they spoke with people in the businesses EVERY WEEK who had Lyme disease. One KU IDSA doctor at KU Med said to me, "there are no ticks in Kansas." We have ticks! We have Lyme Disease! We have a Lyme Disease Research Center in Manhattan! We have had much research take place both here and at NIH!

Jason McGoldrick I'd like to see the IDSA recognize Lyme Disease (and other infections in this disease complex) as chronic infections that may require extended periods of treatment. Or at the very least use some of that dinero on more in depth research. Biofilms, cysts, parasites, etc. Thanks for listening

Peninah Ann To teach administrators of hospitals that they can not deny access to hospitalization based only on the fact that the patient has Lyme disease. Ransom Memorial Hospital told my doctor in Ottawa that he was not allowed to hospitalize me with late stage Lyme disease!!!!

Jason McGoldrick Oh and I should add.... when I was first diagnosed with Lyme an ID Doc prescribed me 2 weeks of Doxycycline and ignored my chronic symptoms present (neurological, knees, heart). I LOL @ 2 weeks of treatment. (Ironically enough it was the IDSA's incompetence that encouraged me to research on my own and take matters into my own hands. I guess for that I should thank you lol

Peninah Ann To walk with every single person that calls a Lyme disease advocate for comfort because the person can not find one doctor in their state who will test or treat their child!

Peninah Ann Stop supporting research that comes against every successful treatment that is found by doctors who actually treat Lyme disease and make people well.

Peninah Ann Stop creating an environment that is more toxic to the patient who is severely ill than the disease itself...the war against the Lyme patient receiving care that works. It destroys the heart.

Peninah Ann To explain why my 17 yr old daughter has had a CDC positive western blot every year for the past 5 years????? without a tick bite? and with long term treatment! I thought you said that the bacteria in Lyme disease does not persist past 28 days of treatment! What happened???
Gretchen Ahlers Roll Call! It's all true, the doctors who denigrate, patronize and ignore seriously sick patients, all because they base their scholarly references on IDSA guidelines and CDC testing criteria...

Nicole Gallagher It's simple- cut the political crap and do your job this year.

Désirée White To each member of the IDSA....God forbid that you or one of your loved ones become a victim of this disease....but consider this...if we (the victims of Lyme), in fact, are speaking truth, then it is entirely possible and likely that some of you and/or your families will become infected and/or affected, and their lives will crumble into nothing and become a living hell. Is that what it will take for this issue to become real to you???

Valerie Mains Wolfer Sue , I hope you don't mind that I'm copying your post.

Sue Larkin Duckworth:
1. I would the responsible members of the IDSA to issue an apology to their organization and to all Lyme patients and physicians for the appalling behavior exhibited throughout the mandated Lyme disease Antitrust guidelines review debacle. Every aspect of it showed disrespect for the panel, the truth, patients, and the medical profession. Other members of the IDSA should be ashamed to have these 'medical professionals' in this organization, let alone be in positions of authority.
2. Acknowledge that Chronic Lyme exists; screening patients with the ELISA test that IDSA Lyme experts knew had poor sensitivity (as low as 50%!), THOUSANDS of patients with Lyme received false negative results by doctors taught by the IDSA that this definitely ruled out Lyme. With a spirochete infestation in their bodies, untreated, for months to years until finally diagnosed by further testing, how can one deny to these patients that their now "chronic Lyme" does not exist? What else do

you call it, doctors? As a Clinical Lab Scientist, I was shocked to learn that a test with such poor sensitivity was being used at all, let alone be used as the sole determinant of negative for undeserved patients, including my daughter, whose childhood was ruined by undiagnosed Lyme. When HIV screens first came out, anything under 90% sensitivity was unacceptable. And improvements came quickly on test kits. But why not the same concern for Lyme patients? How could such a cruelty be allowed to devastate so many people? Why not make this critical information more clear to physicians, so they could diagnose on symptoms as was actually recommended by the FDA so patients wouldn't go untreated as they do now? How can this organization not fully grasp this grave situation and put an end to it?
3. Members of the IDSA must clean house and restore its reputation. Certainly there must be members who are disgusted by the behavior of this IDSA old guard, who are desperately trying to save their reputations at everyone else's expense. There is just too much evidence and too many people harmed to ignore this.

Bruce David Wright Hmmm. Let's see. Perhaps start by looking up the words 'phony' and 'lacky' (drug company) in the dictionary. Or maybe 'joke' (sick)? Opps. Too 'abusive'? (Gee. There must be some drug to take for feeling abused.)

George Harrison There's a church in Oregon City whose members are getting charged and convicted of Negligent homicide due to mis-treating their children with curable ailments. Theoretically, Not doing the right treatments on these children was a crime. If those same standards were applied, How many physicians in this area of expertise would be incarcerated?

George Harrison (By this area, I mean related to Lyme Disease) ;)

Greg Boulden I agree with all of the above Lymes post. I'm a 32 year old whose quality of life has gone downhill over the past two years. I was treated in 2007 and told I was "cured". And since three of the western blots come up negative doctors refuse to treat my chronic conditions, they tell me it's not Lymes, I was "cured" of that. As a result I've been to neurologist, cardiologist, ent's, hospitals... And I'm made to feel I'm wrong for wanting to go to a Lyme literate doctor- which won't be covered by insurance... Cut the crap and acknowledge there are many of us still suffering after treatment.

Cheryl Hamman-Watson Lyme disease is a world-wide issue. I was bitten while in North America 36 years ago, was never treated and have suffered with my health ever since. Recently I was tested positive for Borreliosis and other co-infections. My two children who were born in the past 30 years also tested positive. They could only have contracted the disease through me. Doctors in my home country, South Africa, know very little of these diseases, and this seems to be the case in every English speaking country. In my research on the web I am gaining some idea of the enormity of this problem. It seems the European countries are ahead in this. The IDSA has an opportunity to lead the rest of the English speaking world in this should they have an unbiases relook at the guidelines. They have the opportunity to assist in preventing so much untold suffering,and bring hope to the hopeless. Don't let your opportunity to assist the suffering slip you by!

Rolf Taylor We need treatment. Please help us by opening up your mind!

Anita Hohendorf Kolbe Read all comments carefully and then pull back into a quiet little room and think once again. Why does your view of things such a flood of protest? Could it be that our way is misleading? And then be honest! And remember, your view of things will be played on my back. In Germany and throughout the world.

Sharon Gallagher Be careful everyone. It has dawned on me they may be collecting your names on this site. They refuse to acknowledge this disease so why now? We know who they work for and if this was an honest attempt to help people don't you think they would have by now. All I am saying is be careful. Maybe we should friend everyone under a certain group and keep track of each other to make we gain more control of what is really happen. I believe if they only have so many hits on this site and its not enough for them to worry about you will be ignored.

Michelle Murphy What about those who test seronegative according to the CDC, But are still infected and are refused treatment?

Jason Orloff Until it is possible to isolate the Lyme borrelia organism from most patients with the persistent phase of the disease prior to antibiotic treatment, how is it possible to say with certainty that active infection with the organism does not persist after the IDSA recommended treatment?

Rm Rmm Take immediate action to reverse the criminal suffering inflicted by obstructing progress regarding Lyme. Immediately begin to diagnose/help/treat/cure Lyme patients with testing & protocols that work! All the resources are available; they are just being criminally withheld.

Marcus Davidsson Gary P. Wormser should first of all be sacked from New York Medical College. Then he should be prosecuted by the International Criminal Court (ICC) for crimes against humanity. I kid you not. When you are misleading the general public and misrepresenting science in such a grotesque way you really should take the consequence of your actions...

Sonnen Schein IDSA, why do you delete the comments? You asked a question and you got many answers. Now we want you to answer OUR questions!!!!!!!!!

Jason Orloff IDSA, Will you specifically state what you would need to see to believe that active infection with Borrelia burgdorferi can exist in some people after your recommended antibiotic treatment?

Holly Gryning Bucy To start really hearing all of these

Frank Williams Sr. "In all affairs it's a healthy thing now and then to hang a question mark on the things you have long taken for granted." B. Russel. By spreading your guidelines all over the world you caused so much pain and suffering, that you should finally start to recognize the responsibility and obligation that comes with that act. It is not too late to make a change and accept Lyme as what it is: a global epidemic, that can be hard to diagnose and even harder to treat. Don't expect us to stay quiet and watch our lives going down the drain any longer!

Nadja Flindris So you have to See how many People answere to your question. You dont have delete them. We all are fighting for our live, our children and you delete??????? Shame on you!!!!!

Nancy Baumgartner Group psychosis? I think not!

Sarah Leonard 14 years ago I had 3 tick bites, an EM rash at bite site and tested positive for Lyme disease and also Human Monocytic Ehrlichiosis. I was treated for 30 days and WAS ALMOST SYMPTOM FREE. I begged for ONE MORE MONTH OF DOXY but my md said any symptoms left were residual and that more abx were dangerous and against guidelines of the standard of care. Within one year I was diagnosed by that md and his referrals with ibs, fms, cfs, raynaudes syndrome, gastric reflux, adie pupil, an early awakening sleep disorder and what my new rheumatologist seriously called "a multi-system progressive neurological disease triggered by post-Lyme syndrome." This was a mix of MS, ALS and Parkie symptoms including bradykinesia, micography, muscle wasting, progressive weakness, loss of balance, body jolts where my body would seize and jolt into the air a fish on a line, vision and hearing problems, choking, resting tremor and a movement disorder called chorea with athetosis. My encephalopathy was so bad that I began to go into dementia at the age of 28.

I could not remember my toddlers name or who my husband WAS. HE WAS A STRANGER TO ME. I had insurance but we had to take out a second mortgage for 50,000 cash to pay for my iv Rocephin. Within 9 months I was 95% normal. I have now been symptom free for 12 years. But I am on maintenance abx. If I go off, I decline after only a few days very dramatically. Dr. Stricker of SF SAVED MY LIFE. IDSA, you have been sadly misled. You have become murderers. I was going to be placed in a nursing home at the age of 29 by my husband and mother. I have facilitated the local Lyme group for 13 years now. We have had 2 people kill themselves. We have had a few longterm surviving ALS diagnoses who followed Lyme protocols. You need to pay attention because your society has a rich history of saving lives. But you are helping KILL PEOPLE.
Sincerely,
Sarah Leonard

Sarah Leonard Peninah Ann, I am a fellow lymie and just wanted to say I hear your pain and frustration, but the western blot is an antibody test not direct detection so it in no way proves persistence of the bb organism, just that at one time she was exposed. I believe your daughter is still ill, I just wanted you to know the science of that because your statement was illogical. I am sorry we have all had to suffer so much.

Gill Mcs Ignoring Lyme is a crime !!!

Josh Cutler Everyone contact your local new station. Contact the national ones as well if we get 40% of the posting people to do this we can get some coverage of this.

Contact local newspapers, local congressman. Do work guys. We have done a great job posting here now take the next step that will only take 15 min.

We can and have the power to change the direction of this.

Josh Cutler The Idsa is headquartered in Alexandria VA. Contact NBC 4 they are local to them.
I will post link on how to contact your local congress man and just google info for your local news station. Take the 15 min it takes to make a difference. The power is in your hands. We have been sick and quiet for far to long.

Lisa O'Reilly Peterson An Infectious Disease doctor told me our daughter, 8 yrs old at the time, was possibly exhibiting symptoms from the stress of 9/11 or had possibly been sexually molested because the Lyme titer was negative and it's 99% accurate. Please! I even explained that she had had a rash on the back of her leg the summer before. I followed my motherly instincts and found a doctor that was knowledgeable about Lyme. After 2 yrs on antibiotics, helpful supplements, and a lot of prayers she was better. And she has no ill effects from the long term antibiotics! IDSA listen to what we are saying. The symptoms are real. There are not that many hypochondriacs in the world.

Nicole Randazzo @Sharon Gallagher... We are not afraid that they now know our names. We know their names and it's about time the IDSA and the world know our names and the faces. We have several pages that many of us joined together on fb and in community and nationwide groups. We are smarter and stronger than they think and we are spreading our message. We r sick and tired of being sick and tired and not going to let them control our treatment or decisions.

Jeff Hickson I am posting this a second time. We all need to keep posting. You are the abomination in the medical world. Denying for years the existence of a disease that has now effected 100s of thousands. Chronic Lyme. I was left untreated for more than a decade in a state that adopted IDSA protocols. I became paralyzed, cognition problems, memory loss, speech impediments, constant pain and all because as a group you denied the existence and limited the testing and diagnosis guidelines for Chronic Lyme disease. I had a disease that did not exist and was thus given multiple other diagnoses that would never give me actual relief. I was told that I would never get better. It was all in my head and so much more. It was not until I got myself out of MA and into CT and treated by an ILADS trained MD who feared for the loss of his license that I actually improved. ILADS saved my life. My LLMD saved my life. My persistence to go beyond the garbage that you spew saved my life.

Jeff Hickson What do I want from you? I want you to go away and be replaced with Drs who care more about their patients than their academic credentials. Cannot change your mind as you would admit to being wrong. Accept your mistakes and start helping patients or go away!

Susan Campbell Chris Finkle http://www.businesswire.com/news/home/20120105005605/en/Boulder-Diagnostics-licenses-Lyme-disease-diagnostic-technology

Beate Scholl What do I want? I want you to start helping patients with Lyme! Please, think about your taken oath!

Kathleen Farrell Please enter the 21st century, update your guidelines to include long-term treatment of Late Stage Lyme disease, co-infections, children born with ailments from an undiagnosed mother. It wasn't long ago that no one tested for "Fifth's disease" in pregnant women - now it's been shown to cause failure to thrive in infants and developmental issues. You are capable of change, you are capable of allowing me the medical treatment my doctor orders. My last medication was denied by a pharmacy - REALLY?! - over my doctor. Disgraceful. And, no, I do not wish this on anyone in any of your families as no one should have to suffer what we have over the years.

Josh Cutler Start contacting them directly.
Audrey Jackson, PhD, IDSA's Program Officer for Science and Research, at ajackson@idsociety.org or 703-299-1216.

Sorry they are in Arlington not Alexandria.

1300 Wilson Boulevard | Suite 300 | Arlington, VA 22209 | Phone: (703)299 0200- | Fax: (703) 299-0204

This is the local news station that would cover this. They have covered the Lyme disease debate MANY MANY times. This would peak interest. Take the time just to fill out the form.

DO YOUR PART!!!

Kathleen Farrell No problem, Josh - glad you are feeling well enough to provide the info - I can do the rest!

Josh Cutler Has anyone posted this to Pintrest?

Josh Cutler Thanks Kathleen Farrell !!! Not feeling that well :) In bed with a laptop just trying to do my part. We need proper guidelines,tests and people working on a cure.

Carrie Garman thank you all for speaking up for us here. I seriously thought I was going to die a few weeks ago. All these comments need to be seen and something drastically changed to help Lyme patients before anymore lives lost. I am only 44 and My children still need me here on this earth! Please please HELP us make it where MD's will treat us as they would treat their own families and not just a file number and sent off to die!!!!

Gretchen Ahlers Good morning Jason Orloff! The questions that Lyme brings up require creative, open minds. Beginning to care about the suffering of people like Sarah Leonard requires a passion for medicine. The starting point is that issue of certitude that you raise. This is a philosophical concept and one that is not always applied in atypical diagnoses such as Multiple Scleroses of atypical origin or whether a person with cancer is going to die of stage four cancer in three months or three years. There are medical questions that, like the question of whether God exists or not, can be reasonably raised by the evidence that exists or not. I can say, "well the sky is so beautiful today, there must be a loving God behind all of this". I can't say for a fact that there isn't a God because there is so much evidence around me that there is a God.

Jeff Hickson . . . . *We all need to keep posting. You are the abomination in the medical world. Denying for years the existence of a disease that has now effected 100s of thousands. Chronic Lyme. I was left untreated for more than a decade in a state that adopted IDSA protocols. I became paralyzed, cognition problems, memory loss, speech impediments, constant pain and all because as a group you denied the existence and limited the testing and diagnosis guidelines for Chronic Lyme disease. I had a disease that did not exist and was thus given multiple other diagnoses that would never give me actual relief. I was told that I would never get better. It was all in my head and so much more. It was not until I got myself out of MA and into CT and treated by an ILADS trained MD who feared for the loss of his license that I actually improved. ILADS saved my life. My LLMD saved my life. My persistence to go beyond the garbage that you spew saved my life.*

Kathleen Farrell Now it would be interesting to see if they email me back!

Josh Cutler Thanks Kathleen my prayer that ALL reading this thread would see my post and contact the proper people that are listed.

Josh Cutler OK folks here is all the info you need, except for your local news outlets. Doing this will take you 5 min and could save our lives and those in the future from further suffering. Info below. Don't just TAKE ACTION...

All I ask friends and family is that you READ THIS, Share it and pass it on. We are trying to get this spread QUICK. If you could take 15 min to read the case become informed and submit this to a local congressman, local news station/paper.

If you read all the people suffering in an unjust manor you will understand. I beg and plea that you would read. Only We the people can stop the suffering of innocent people.

Again PLEASE read this thread. If you could also help we are trying to get NBC 4 in Wash DC to cover the story if you could share your opinion via the link below.

Also, I have left contact info for the IDSA if you would to contact them for questions. Have a good day. Please do the right thing. 15 min of your day could change the lives of hundreds of thousands of suffering people.

Audrey Jackson, PhD, IDSA's Program Officer for Science and Research, at ajackson@idsociety.org or 703-299-1216.
Sorry they are in Arlington not Alexandria.

1300 Wilson Boulevard | Suite 300 | Arlington, VA 22209 | Phone: (703)299-0200 | Fax: (703)299-0204

This is the local news station that would cover this. They have covered the Lyme disease debate MANY MANY times. This would peak interest. Take the time just to fill out the form.

DO YOUR PART!!!

http://www.nbcwashington.com/contact-us/

https://writerep.house.gov/writerep/welcome.shtml

Josh Cutler Here sorry forgot the link...

https://writerep.house.gov/writerep/welcome.shtml

Write Your Representative - Contact your Congressperson in the U.S. House of Representatives.
writerep.house.gov
The Write Your Representative service is provided by the U.S. House of Represent...

Kathleen Farrell My prayer is for you to start feeling better - at least you have a laptop! Unless I'm sitting at my PC, I'm not online - no fancy phone or anything.

Martha Fisher I would to see the "Lyme wars" come to an end and see patients treated for Lyme disease until they are cured. If there is no such thing as chronic Lyme what are all the people talking about who have it? Please read the writing on the wall and do whatever it takes to educate all doctors in epidemic states. If ID docs are at the forefront of treatment they need to work with patients, not against them, urge insurance companies to stop denial. The problems from chronic Lyme cost far more than sane treatment in the first place. It is a no brainer that the ISDA and CDC need to seek a true cure for this horrible disease. Please end the ridiculous debate and listen to all the truly sick people and hope someone you love does not ever contract Lyme.

Gretchen Ahlers Jason Orloff, To continue, It cannot be said with certitude that active infection DOES NOT exist as is the case with Sarah Leonard. General practitioners who have not chosen to become experts in infectious disease rely on IDSA guidelines and end up dismissing patients who continue to be very sick after that little bottle of doxycycline. The issue of certitude in guidelines could go the other way. It cannot be said that Lyme Borrelia is NOT present when a person continues to degenerate, as Sarah leonard did, in vital nervous functions in the body including those nerves that are responsible for cardiac and respiratory innervation and crucial temporal lobe functioning. The theory of epitope spreading helps to explain the phenomenon of failure to manufacture positive long term antibody response. So....the scientific questions involved with Lyme Borrelioses are still questions that require research. To assert that this is not so, empowers insurance and doctors who only ascribe to guidelines and protocols. It disenfranchises the very real voice of the sufferers who know their own certitude which is that they are facing a horrendous disease with very little medical support, despite their tax dollars and steep insurance payments. In fact, the debate is so acid that this is taken out on the sick and suffering and they are denigrated and cast out. Let's get back to what can be certain and what cannot and have an inquiring mind, one that knows that the truth will be revealed when we really seek for it.

Gretchen Daniels, RN BSN

Mary Ann Mazzarella I posted way up the list but have another idea if anyone is really out there listening and cares. It's obvious Lyme Disease is an issue considering everyone answering your question mentions Lyme. I havent heard a word y other disease here. Set up another FB page or web site just for us Lyme people and families of people with Lyme. Let us tell our stories, post pics, list all the drugs we have tried and are on. Maybe the IDSA can learn something and do something to stop this epidemic and people from suffering.

Joy Birdsey I would like to see truth and justice for Lymes and ME, I am not sure what I have had for 20 years, dx ME but no tests and I live in an area of many ticks and the amonophalis (think thats how you spell it) mosquito, and organophate spraying up to our garden fences, due to Toney Blair recinding the 3 metre rule on agro spraying.

Joy Birdsey Also the medical insurance companies exposed for cover ups of Lymes and ME

Summer Bushnell Do a long term study on Lyme people to prove or disprove the disease.

Mary Ann Mazzarella I'm guessing this won't stay up long...I just Googled 3 of the 12 Dr's who authored the guidelines. I plan to look up all 12 but the 3 so far have terrible ratings from patients. These are the people that are basically writing the manual for other dr's on how to care for their Lyme patients. Disgusting.

Kelly Patterson Recognize Lymes and help my friends who are suffering greatly from it's effects.

Nancy Cargell 1)Listen to patients; 2) Understand the hopelessness and helplessness that those with persistent syptoms experience; 3) Work with ILADS physicians to cooperate on research that gathers the facts rather than searching to support what is believed to be true; 4) work to identify the complications that occur with co-infections; 5) work to improve tests and diagnosis; 6) open your collective mind to the concepts that ILADS physicians consider regarding improved outcomes with different antibiotic combinations, pulsing, switches, and their timing based on symptoms; 7) find out more about the different forms of the spirochetes; 8) research immune support because it's highly unlikely that science will - anytime soon - figure out how to test for ALL the pathogens that cause infectious diseases and the real key to treatment will be in unlocking the mysteries of the immune system and persistence of pathogens in dormant states; 9) improve your collective compassion for patients with persistent symptoms so that you can better understand WHY these patients are willing to go to the extremes that they do in order to relieve the symptoms and try to be cured.

In 2013, after you've moved in the direction of the above, you can work on disseminating results of GOOD research, educating physicians, and working with insurance companies to proactively address immune diseases. Thank you for asking.

Valerie Mains Wolfer IDSA deleted my comment from yesterday so I am reposting. My story is like so many others suffering. For years I was told I had a poor immune system...then I was diagnosed with CFIDS and told by an ID doc that my level of functioning was below many of his AIDS patients but unfortunately there was no effective treatment for CFIDS yet. I was put on disability and continued to progressively get worse and then finally after numerous inaccurate tests for Lyme, a knowledgeable doctor whispered to me that I needed to see a Lyme literate doctor immediately because I had almost every symptom on the list including brain lesions. Unfortunately, after 30 years of various health issues I found out too late that Lyme was the cause and am not responding to treatment as hoped.

To add insult to injury family and friends are repeatedly told Lyme Disease is no big deal or that it doesn't exist by their own doctors so they cannot begin to fathom the living hell my life has become. In what world is it no big deal when a person has all of the following: brain lesions, seizures, tremors, inflammation, profound fatigue, daily flu- symptoms, compromised immune system, autonomic dysfunction, severe cognitive issues, lymphatic disease, chemical sensitivities, neuropathy, joint deterioration, autoimmune diseases of the thyroid, lungs and cns, relenting joint, muscle and nerve pain and more recently problems detected with the heart, kidneys and liver. No big deal...I think not IDSA!

Alana Lofgren Quite simply, to revisit guidelines and revise Tx protocols for Lyme and Co's based on empirical and REAL scientific evidence that Lyme knowledgeable MD's know is working. This is a devastating, life and finance sucking illness...ignorance and denial is not an option!

Valerie Mains Wolfer For those who are well enough, please take the time to get this thread to news media outlets throughout the country. I'm sure one of them will pick it up.

Britten Kilduff I would love for you to actually take an objective view on the testing guidelines for Lyme in 2012. Do you think hundreds of thousands of people are that starved for attention they would create a disease that is "all in their head" by your definition. Why are you so afraid to have an outside panel review the information and make an informed decision on the material that has been presented? An outside and fair review would not constitute a panel picked by IDSA members and formed almost exculsivly of IDSA members. Lives are at stake, isn't that more important then money and prestige? Please go back to the oath you took when becoming a MD and "do no harm."

Dolores Claesson Can you please post the questions on zoonotic pathogens that the ID docs must pass for board certification ? Are they listed ?

Andy Lautin The following is a word for word transcript of a clinical note authored by Dr. Wormser - Let us see if the IDSA has the merit to keep this on its site for all to read and for all to draw their own conclusions.
I went to see Dr. Wormser on 5/30/97 because I was unwell, and Terry (my wife) entertained the possibility of Lyme (searching the Web led her to this possibility. And searching the Web led her to the name of the Lyme

specialist - Dr. Gary Wormser - at Valhalla, Westchester Medical Center).

Dr. Wormser's note (annotated by me) is reproduced immediately below:

48 y/o WM psychiatrist from Yorktown Heights x 2 - 3 years.

1 1/2 years ago vertiginous, impaired concentration. An MRI revealed left sphenoid sinus was opacified. Also had positive Lyme titer (1). Underwent surgical drainage, then felt better but relapsed. Two weeks later a Lyme test was repeated which was positive (2). Saw Dr. Yankowitz (3) And he saw a neurologist. The CT, LP was negative (4)

Doxycycline 100mg po bid x 3 wks x 1 year gap. And then he felt better. But not lasting (relapsed while still on Rx). Changed to Augment for 2 1/2 weeks and felt better.

Five weeks ago mitral repair (5). For several weeks preceding surgery had recurrence of dizziness (but received no dx.) Post-op didn't feel well at time of discharge..

Currently doesn't feel well.

Temp 99.5 - 99.8 rectally, feels better on NSAID.

PE: Normal.

Imp: Dx unclear but NO REASON TO IMPLICATE LYME (5) in the post surgical complaints.

Dated 5/30/97 (6)

1) The positive Lyme titer was obtained at the time of the sphenoiditis was identified. I was very dizzy, ill and and CT revealed an opacified sphenoid sinus. The radiological indication was clear. ENT surgery.
2) The result of an ELISA drawn on 12/27/97 conducted by Stony Brook Lyme Lab was 3.34 - Four times the upper limit of normal.
3) A Beth Israel infectious disease attending.
4) Dr. Wormer put the word negative in quotes for emphasis.
5) I evidently was born with a floppy mitral valve. Satisfactory etiology for congenital MVP is not available.
5) Caps, for emphasis are mine.
6) As noted ELISA was 3.34 or Five Times the Normal Limit. On the same day a WB (SB Lyme Lab) revealed eleven IgG bands and one IgM band

This opinion rendered by the expert on Lyme at Westchester Valhallan Medical Center.
This is perfidy
My name is of no consequence in the sense that everyone is exposed to this. The IDSA members have family, or extened family outside playing in the woods right now.

If you have any concern for your own health or the concern of the health of others, Anyone, everyone say something, say anything.
But I will provide my name - Andrew Lautin MD

Tammi Baker Ziccardi I too would like you to update the Lyme disease guidelines so insurance companies will pay for treatment and doctors can help their patients without fear of losing their licenses, develop superior testing, and listen to and integrate the research that is being done outside of your society. I have seen first hand a beautiful and vivacious young mother and wife become house bound, helpless and fearful. This disease robbed her of precious time and experiences with her small children, husband, family and friends. She went through months and months of countless tests and criticism only to be told many, many months later that she has advanced Lyme disease and damage has been done. It is a very real and devastating disease that needs immediate attention to help those who need it. What will you do to help this growing problem?? I want to know! Please don't turn your backs on this harmful disease!

Dolores Claesson Come now let's be nice...let us make up some questions for their board certification ?

Dolores Claesson I am sure you want patient involvement ?

Dolores Claesson How about some involvement from Biologists/chemists and researchers in the ID arena ? DIALOGUE is a good thing....dictatorship does not work.

Dolores Claesson
http://www.avma.org/public_health/zoonotic_risks/hunters_precautions.asp
Disease precautions for hunters
www.avma.org

A general guide about zoonotic and other diseases that hunters and their hunting...
See More

Dolores Claesson Hey there are quite a few missing but it is still a good list...too bad veterinarians can't treat humans. They seem to have more of a handle on zoonotic pathogens.

Andy Lautin The two figures on the left - these postures could be bilateral hemiballismus (caught on a picture) secondary to insult to the subthalamic nuclei bilaterally. And this (if these poor folk saw Dr. Wormser for evaluation) secondary to Dr. Wormser's antinosological and anti treatment bias. Cytokines/microbes can do nasty things in the rostral brain stem.

Ruth Thomas I have been deleted twice. Both times I requested acceptance of IGenix test results. Is this a sore spot? IDSA doctors ignored my IGenix results and took away two years of my life. Your guidelines are WRONG. We should collectively sue if there are not significant changes within the next year.

Rick Shaw *I challenge the IDSA panel to be injected with the blood from just one the now "healthy people with Post Lyme symptoms" if their findings are true they have nothing to worry about, RIGHT?!?!?*

Dolores Claesson *Once an ID doc knows a Lyme/morgellons patient they get it ! They realize that those guidelines should be thrown away.*

Angela Rivers A more widespread acceptance that this is a serious disease and should be looked at more carefully by the entire medical community not just LLMD's. It would also be nice if insurance could help pick up some of the cost that us suffering could use to get proper treatment. Stress makes the immune system worse and is harder for people suffering from Lyme to heal during times of stress....Proper treatment and cost coverage would aid in the healing process.

Dolores Claesson HEE HEE ! Carina Rodriguez MD ped ID doc told me that my daughter had hormonal issues and that they saw this in high achieving girls...she wasted my cell phone for that ? Let's see she is IgM + for Borrelia, Babesia duncani, Ehrlichia Chaff, Bartonella, and Brucella and has shown antibodies to Parvo B-19 and papillomaviruses and IgM + for Hsv 1 and has low IgG sub classes. The problem is the caliber of ID docs. David Berman also misdiagnosed when the bloodwork was in front of him. The head of ped ID at Duke had no idea what the blood work WB was for Lyme and by the way she has an ELISA of 2.19 and + WB at QUEST !

Dolores Claesson One of my good friends used to be an ID doc and I now know why he left this field.

Dolores Claesson My WB came back positive and Cynthia Mayer DO ID told me to go to NY but not to come back to her cause she knew nothing about Lyme....

Dolores Claesson I think we should give you the names and phone numbers of all the Infectious disease physicians who have willfully misdiagnosed us... Thanks to Cynthia Mayer cause I did see and ILADS doc !!

Dolores Claesson One of my friends (pediatrician) told me that I would find no help from any pediatric ID docs here in FL and recommended that I fly north. Not everyone has the funds to hop a plane to see a doc who will test/treat them ! We have migrant workers suffering with this !

Infectiously Optimistic Last year, a number of writers came together to write a series entitled "My Lyme Disease is Not The IDSA Lyme Disease". Personally, I believe that stories and the account of our experiences speak louder than anger and frustration. Each story shared illustrated the pain, suffering, and debilitation of those who are struggling with Lyme Disease. Yet, each story also shows the courage, strength, and endurance required to keep fighting. I believe that this is a far more effective way to honor the truth, rather than commenting out of frustration and ire. Please see the bottom of the following article to find additional stories and posts.
http://infectiousoptimism.blogspot.com/2010/12/my-Lyme-disease-is-not-idsa-Lyme.html

Rick Shaw I challenge the IDSA panel to be injected with the blood from just one the now "healthy people with Post Lyme symptoms" if their findings are true they have nothing to worry about, RIGHT?!?!?

Jeannie Bonetpels Dear IDSA doctors, I have been misdiagnosed for 16 yrs. Bedbound for seven years. Missed out on my three kids growing up and now my two grandkids. I am currently in treatment thanks to a wonderful ILADS doctor. Today, because we are trying to kill what is in my body, I'm in bed again. The worst part of that is that I am at my elderly parents house for the weekend to care for my elderly mom. But she is caring for me this weekend. That is horribly wrong. I want my life back and I know that you need and should change your attitudes about this awful disease. It isn't going away, one of these days and with the internet it will explode in your faces of all the sick people. HIV gets more attention yet Lyme Disease has 10 times more sick adults and the poor children. Please, for your sake take precautions when going to the great outdoors or even sitting on a park bench. This could happen to you or your families no one is immune. I'm sick and tired of being sick and tired. Don't turn a blind eye to this, because it's not going away. We aren't going away.

Dolores Claesson Dr Dale Bergamo ped ID doc stormed out of the hospital when they told him to come see my daughter in her hospital bed....he was ill prepared for someone who loves their child and had done so much research !! COWARD !! How about reprimanding these ID docs who have behaved so badly ??

Dolores Claesson Come out fellow lymies give some names of the ID docs who slammed the phone in your ear ?

Dolores Claesson Mobeen Rathore is another one...he told me I could drive to see him but he may or may not see my daughter. Hell is too good for these ID docs who are mis-treating patients and then I know some good ones but can not give their names for fear of retribution. We will take over the IDSA because we will find ID docs with a conscience.

Dolores Claesson Once an ID doc knows a Lyme/morgellons patient they get it ! They realize that those guidelines should be thrown away.

David Koronet I would like to see some good research on what treatments are effective for Lyme disease. I see a lot of invective here, but the reality is that the three week protocol hasn't been put through any published papers that I know of - it is as much conjecture as every other Lyme treatment. What works, what doesn't? Please put the research money into that, rather than the fruitless quest for a Lyme vaccine.

Dolores Claesson ALL Children's Hospital in St Pete is knowingly telling people there is no Lyme in FL when the State Board of Health has us down as an endemic state. Call Juan Dumois and ask him what he has done to CHILDREN !!

Nadja Flindris Write more !!!
Again and again!!!!!
they have to change it!!!!!
We are watching you from Germany!!!!!!!

Christine Keller Lyme Folks, please let's keep our posts informative, include your state of origin, and stay on task, let's attempt not to debate here but to objectively state our meritorious cases that the IDSA and the media, and our legislators will take the info seriously. Some people think their posts are being deleted, but you have to remember to go back to the time you posted, with FB only showing increments of the most recent 50 out of over 1600 posts. I'm with you all, and n the IDSA to Hitler in its mass murder and willful and knowing destruction of lives, complete mistreatment, and not backing insurance coverage for the billions in unnecessary medical accumulated to date as a direct result of the IDSA's corruption. I ask each of you to contact your local CDC and you states Attorney General, I'm attempting to start a movement ned to the multi-state class action suits against the tobacco industry, but I can't do this without each of your help - every one of you needs to participate to see results, this is where your voice and action can make a difference! I'm also asking folks to contact national media on this issue. It is very important you post your state/country of origin, so the investigation into this movement reflects nationwide concern - not just localized populations. Help me help you folks! Post constructively, include state, contact your state's AG and CDC, email your local/national media. story@nbcuni.com, letters@msnbc.com. Thank you!

Joanne Drayson Excerpt
It was obvious to participants at the workshop that a significant impasse has developed in the world of Lyme disease. There are conflicts within and among the science; policy; politics; medicine; and professional, public, and patient views pertaining to the subject, which have created significant misunderstandings, strong emotions, mistrust, and a game of blaming others who are not aligned with one’s views. Lines in the sand have been drawn, sides have been taken, and frustration prevails. The “walk in the woods” process of conflict resolution or a similar process seems necessary

for creating a new environment of trust and a better environment for more constructive dialogue to help focus research needs and achieve better outcomes. Such a process does not imply a compromise of the science but rather is needed to shift to a more positive and productive environment to optimize critical research and promote new collaborations. http://www.ncbi.nlm.nih.gov/pubmed/21977545 If only the IDSA would read this paper they would realise that 'Significant Gaps Remain In Understanding of Lyme Disease.'

Cindy Hall Clark IDSA, please stop deleting our posts"

Michelle Newell We need doctors who are NOT enjoying conflict of interest monies lining their pockets, to get together and write the guidelines for treatment of Lyme disease. Our children are suffering - all for the sake of money lining the pockets of a few corrupt individuals that create guidelines that save insurance companies a few bucks or the thought that they can patent the next great vaccine. The cost to society to have to care for those who are too ill to work or must quit work to take care of their ill children is enormous! The cost to society and to personal well being of not treating is so much higher than treating a person with Lyme disease. Doctors are being hunted like animals and denied their livelihoods if they treat patients with Lyme disease. I personally would rather die trying and willing to take any risk of antibiotic use to fight Lyme disease than to die a horrible, painful and debilitating disease that takes my physical and mental abilities away one small piece at a time.

Shari Orton Albertson Lyme Disease has taken my future away from me, I doubt that I will ever enjoy my grandchildren, and wonder if I will be able to work long enough to earn a pension to support myself in the future. So much money is wasted in this country .. in the world for that matter, and you have in front of you one of the biggest cripplers known to man, yet you make it difficult or impossible for people to get treatment. It is shameful that you are not taking this seriously and holding us hostage to this disease. We need more research on reversing the damage, preventing its continual degeneration of our bodies and minds, and we need access through our medical insurance to pay for treatments. This is what you are suppose to do, so what are you waiting for?

Karen Hassan In spite of CDC positive WB from Spinal Tap, ID docs told us our son "absolutely did not have Lyme Disease". My son is one of many young adults who are on disability because of delayed and inadequate Lyme treatment. After 4 1/2 years of treatment by an ILADS doctor, he is much improved. The research is out there and available to all, showing the persistence of borellia after the "magic" 30 days of abx.

Kim DeSantis Goodwin I had to diagnose myself and my husband after years of drs throwing out incorrect diagnosing. I even had surgery for no reason. After knowing what I had even without any memory of a tick no, no red rash and not the routine symptoms after looking at real people and the non Dr sites I finally knew for sure what we had. How did I figure it out and 10 drs couldn't and close to 19 between my husband and I. There is something very very wrong with this picture.

Helen Fasy I used to be an OR RN. At the extremely healthy age of 37 I was infected with Lyme disease and several other tickborne diseases. I had a bulleseye rash (large) on my left thigh. Sadly, in 1987 I didn't have my "PhD" in understanding all tickborne diseases then. Although I had symptoms almost immediately I had no idea how severely ill and incapacitated I'd become. At the same time our then 9 yr old healthy daughter began feeling very ill. Fever, excruciating pressure headache 24/7, painful knees extreme fatigue. We took her desperately to 12 doctors. /even the head of pediatrics at CHOP in Phila PA. We were told everything from it was from her jaw. to aversion to school (she adored school...very bright, many friends) asked us if we were abusing her and why not concentrate on something positive to "take her mind off of it". Our daughter was very ill, in extreme pain and finally began to have vision changes. We were losing her. finally we found an angel MD who saved her life. After a lumbar puncture while hospitalized to be immediately treated for Lyme disease, it revealed she had pseudo-tumor cerebri and papellidema. She began IV antibiotics and had a severe jarish herxheimer reaction. As she continued IV treatment then oral antibiotics and diamox we prayed for a complete recovery. One day she walked slowly down the steps and said "mommy, my head doesn't hurt anymore".

She continued to improve as the treatment continued until we got our little girl back. The happiest day of our lives! I continued a downward spiral and knew I had Lyme disease and probably other tickborne diseases. Horrific pain began in my face, gums brachial plexus....all my cranial nerves along with slurred speech, inability to walk alone and severe "brain fog". Encephalopathy. My left side began to be weak, I had Bells palsy and extreme fatigue. My pain was so terrible we began our search for an experienced pain MD. Finally A wonderful board certified pain management MD, a neurologist, saw me and treated my suicidal level pain correctly. She understood Lyme disease, amazing! Before I got proper pain treatment I was seen by several dentists since initially the pain felt it was in my teeth. I had 6 root canal surgeries done (no pathology) a TMJ arthroscopy (no pathology) sinus surgery (no pathology) and finally the extraction of all my uper teeth. Agin, no pathology. I was incapacitated by this ungodly pain and desperate.

A LLMD (Lyme literate md) finally correctly dx me in 1993. 7 years after the bulleseye rash. I responded to treatment almost immediately and felt so much better after my jarish herx reaction. Unfortunately, I was told that I could stop antibiotic tx since I felt about 90% better. Big mistake. Within 7 days I became so ill my husband took me to the ER. The pressure and pain in my head and elsewhere caused me to vomit uncontrollably. Despite the terrific pain management I was getting, it couldn't stop this. After getting IV dilaudid in the ER the pain diminished. I'd had all the brain scans etc previously. My SPECT scan at Columbia Pres in NYC had showed severe hypoperfusion both cortical hemispheres. My neuro psych evaluation results were pitiful. I too then began IV antibiotics with amazing results but within 10 days it was stopped. Despite always having "cadallac level PPO" for health insurance through my husband's corporation continued treatment was denied.

I was finally seen by a well respected LLMD who resumed IV treatment. Again I began to come back from hell. My husband has spent enormous amounts of time fighting with insurance companies. Finally for quite awhile it was covered. I was finally diagnosed with babesiosis, ehrlichiosis, bartonella HHV 6 and 8 CMV and mycoplasma. Being tx for babesiosis with mepron/zithromax was a miraculous time. I improved a great deal.

My husband began to have severe fatigue, almost constant heart palpitations, brain fog numbness. He too had Lyme disease and required IV antibiotics. Many times he called and told me he couldn't find his way home. I'll never know how he kept working with his picc line hidden under his dress shirt and managed many people.

finally the summer before our other daughter was to begin college she too was exhausted, had severe headaches and encepalopathy. She too began IV antibiotic tx. Followed by oral antibiotics. Both daughters husband seem better today. Both daughters either relapsed or were reinfected about 6 yrs ago, both back on IV antibiotics followed by orals. Unfortunately, I remain chronic. To sustain about 40% of my former healthy self I continue lifesaving treatment to this day. We've had some positive tests but no test exists today that is 100% accurate in diagnosing these tickborne diseases. Every other illness known to man has been ruled out. Every test known to man has been done. Due to an unavoidable situation I wasn't able to take my meds for about a month. I became literally "ICU" level sick. After resuming tx, within another very difficult – difficult 8-10 days I was able to sit up in bed, walk again and resume my much appreciated level of function.

The costs of denied multiple life saving IV antibiotic treatments etc have devastated us financially. That along with my husband and many others in upper management in his corporation being downsized (nice way of saying you've lost your job at age 55) added to our dire financial situation now. I've been disabled due to neurological damage for quite some time. Please agree to revise your guidelines. Consider the enormous amount of evidence showing that chronic Lyme disease exists as well as other tickborne diseases. We have bought and sold several homes with corporate moves. We all were extremely healthy before being infected with tickborne diseases. Nobody would choose this life if they had a choice. I wouldn't wish it on my worst enemy. I will die if I do not continue my life saving treatment. Despite everything, I want to live.

Again, I respectfully ask you to reconsider the countless people and families who suffer and have had to fight for treatment we know we must have in order to have a chance at living. The delay in treatment and diagnoses of these diseases is causing so many of us to become disabled or worse. The devastation to families affects every facet of our lives. Thank-you.

LouAnn Martin Please consider Lyme disease as an infectious disease.

Sara Schultz IDSA, please stop representing the insurance companies and the pharmaceutical industry, and start upholding your true obligation: to protect the public from preventable disease, needless suffering and death. The IDSA (and its partner in crime the CDC) can continue to suppress the reality of undiagnosed and untreated Lyme disease --but you will NEVER silence the truth.......................................

Bobbyjoe Holliday http://youtu.be/dzAduXFyISU

Where have all the Flowers Gone
www.youtube.com
A story of the song in pictures

Bobbyjoe Holliday
https://www.facebook.com/events//

links to all Morgellons pages
Thursday, April , at :am at Facebook

Bobbyjoe Holliday where will our children be in the not so distant future

Kathleen Dickson Well, I don't know what they think they're talking about. Ticks only result on bad-knees in Connecticut, and OspC is associated with brain invasion, which everyone knows does not happen. Lyme is just a knee. And anyone who says otherwise has "some psychiatric illness," according to Allen Steere, et al.

Stacey Tumlinson *Acknowledge and learn how to treat Chronic Lyme Disease from people who KNOW HOW! Ask Chronic Lyme sufferers what works for them and talk to the doctors that successfully treat them. Stop calling it Fibromyalgia and saying there is NO CURE.*

http://www.ncbi.nlm.nih.gov/pubmed/

Genotypic Diversity of an Emergent... [Vector Borne Zoonotic Dis.] - PubMed - NCBI
www.ncbi.nlm.nih.gov

Kathy Obal Carlstrom IDSA, it seems to me that you are deleting comments that contain neither fowl language, nor attacks. Truthful comments about the seriousness of Lyme disease and co-infections that unfortunately for you expose your serious failures as an independent medical organization (with little, if any accountability) have apparently been repeatedly removed from this dialogue. As you keep deleting relevant and non-attacking comments by Lyme patients, it becomes clearer that there is a cover-up of the facts and truth about Lyme and other serious infectious diseases by the IDSA that endangers the health of this nation and others. Is this what the IDSA is about? Your true colors are becoming ever more apparent and it may be well overdue,,, time for further state and local government legal action against your organization, federal government intervention and a call for the removal of a number (if not most) of your compromised board members.

Patsy Swinson Whenever I meet someone with Lyme symptoms, I tell them they need to be tested for it, but never with the Elisa and whatever they do, DON'T go to an infectious disease specialist because that has become synonymous with NOT getting a diagnosis or getting well. I shouldn't have to give such sad advice. Something is VERY WRONG here, and it's not just the fact that there are so many people with Lyme. Why aren't you embarrassed about the fact that you're not doing your jobs?

Kathleen Dickson CDC officer Alan Barbour says OspC is associated with brain invasion, so he must be delusional. IDSA says there are no brains to invade.

http://www.ncbi.nlm.nih.gov/pubmed/9234797

Immunologic and genetic analyses of VmpA of a n... [Infect Immun.] - PubMed - NCBI
www.ncbi.nlm.nih.gov

Kathleen Dickson But we know that would be only on IDSA's part.

Sara Schultz I would also like the IDSA to explain to me how I could be bitten by a tick --in a known endemic area --develop a distinctive Bull's eye rash --followed by classic symptoms of late-stage, disseminated Lyme disease, yet countless doctors in Canada refused to even consider the POSSIBILITY that I might be suffering from late-stage, untreated Lyme disease?

Kim DeSantis Goodwin When reading these comments does the IDSA think they can keep using the excuse of

antibiotics long term are dangerous. iDSA our bodies our decision when you can't breath or sleep you are in so much pain. Also knowing that organ by organ, muscle by muscle and the damages to every piece of your body do you think we don't know to use probiotics and take things to support the antibiotic use. It doesn't come close to living untreated with Lyme and co infections. That excuse is overused and needs to stop being used. None of us want to take anything by choice.
We didn't ask for some sicko to turn Lyme into a weapon to hurt humans. This is why our animals are easily treated and humans aren't. It was changed to trick the human immune system and attack our body in confusion and its time you call it an autoimmune disease. Studies show in a test tube with strong antibiotics with the Lyme bacteria alone never mind the co infections, does not kill all the Lyme. This is proof that 21 days for one wouldn't ever be enough and with Lyme turning into 3 forms and hiding deep within the body it would take so long to get it all. I am on month 10 and every month i notice improvements but i know it will take me another year or so to be ready to stop antibiotics. I also take 30 supplements a day, bought a infrared sauna, rife machine, drank peroxide, mms, hypobaric oxygen chamber therapy, no sugar and the list goes on and i went untreated for 5 years.

What about people that have had it their whole life. Im terrified for my daughter not knowing if this will just go away or if it will come back and harm her later in life. Soon you won't be able to cover this up anymore to many people have it now, spreading the word on the truth, the celebrities are getting it and speaking out. Soon the wrong person or should i say the right person will get it find out the truth and millions more will know the truth. i feel even worse for the millions walking around thinking they have MS, Fibro and the long list of wrong diagnosis. All along never had it and wasted their life on drugs they never should have been taking and the bacteria kept growing all those years. The fda can't stand the thought of losing money with people being on all those drugs when Lyme drugs are not forever the other ones are.. ashamed of living in the US

Paula Gallo How about setting up some big rife machines for people to use? That works too.

Karen Miller IDSA, here is your mission statement: The Infectious Diseases Society of America (IDSA) represents physicians, scientists and other health care professionals who specialize in infectious diseases. IDSA's purpose is to improve the health of individuals, communities, and society by promoting excellence in patient care, education, research, public health, and prevention relating to infectious diseases. Our Core Values

Enhancing care of children and adults based on sound scientific evidence

Advancing the discipline of infectious diseases as a foundation of medicine and public health
Promoting and sharing knowledge to reduce human and societal toll from infectious diseases

Advocating for sound and humane public policy

Promoting collaboration and cooperation among, and services for, members and other professional colleagues

Brittany Goff i would love to see all the Infectious Disease doctors stop being cowards and denying the proper treatment to Lyme disease. months of antibiotics and i feel amazing, no thanks to you....

Karen Miller Continued: IDSA, read your mission statement- and after that, read these comments from the public. The only logical conclusion one can draw is that you have failed in your mission. Read your core values- you have failed items 1, 3 and 4. You have failed to adhere to most of your core values. My question to you: What do you plan to do to exonerate yourselves?

Carl Tuttle The Tuttle family was featured on New Hampshire Chronicle's "Living with Lyme" with the program archived on their site in six small segments for viewing on the computer.

http://www.wmur.com/chronicle/24181311/detail.html
Although our story takes place in New Hampshire, faulty Lyme diagnostic tests are missing tens of thousands of cases worldwide every year.

Based on the universal misunderstanding of lab results, I have constructed a website highlighting the plague of ignorance as it relates to the misdiagnosis of Lyme disease. Please feel free to pass this along to others. (A must read)

New Hampshire Lyme Misdiagnosis:

http://home.comcast.net/~runagain/site/?%2Fhome%2F

Our “perspective” on Lyme disease comes from first hand experience as all family members have been afflicted with this disease. What we find most disturbing is the fact that our family practitioners knew absolutely nothing about Lyme disease, had a universal misunderstanding of lab results and a universal dismissal of Lyme symptoms. None of our family members presented with a bulls-eye rash and only our daughter recalled a tick bite. In the absence of the bulls-eye rash, the lihood of obtaining a timely diagnosis in a state with the highest reported number of Lyme disease cases is virtually nonexistent.

Every patient attending the monthly Lyme support group meeting has a similar story. The misdiagnosis of Lyme disease is rampant in New Hampshire fueled by faulty diagnostic tests. The first line screening test for Lyme (Elisa) is producing false negatives and everyone is told they do not have Lyme disease. A follow-up Western blot test which is much more sensitive is forbidden when the Elisa is negative. The Western blot is only allowed after a positive Elisa to rule out a false positive. How do we rule out a false negative?? We don’t!! (This is criminal)

Faulty diagnostic tests are creating confusion within the medical community causing the physician to miss the narrow window of opportunity for successful short term treatment which is now creating a backlog of late stage Lyme disease patients.

Carl Tuttle
Hudson, NH

June Whitehead stop erasing posts we wont be ignored and left to suffer any longer!!!! acknowledge the fact that the elisa test and the guidelines are flawed leaving innocent people and children to suffer and die!

Wendy Vogt "What you do to get through the day is nothing short of heroic.” That is what my doctor said to me multiple times as he watches me battle my way out of Lyme and Bartonella and Babesia. Those words are for every person who has posted here and for every man, woman, and child battling this disease. IDSA can either be part of the solution or get out of the way. Change is happening. And so far, IDSA legacy is going to be unchecked epidemic and tainted blood supply. That is how history will write about your actions... if I was you, I'd make changes now.

Stacey Tumlinson Acknowledge and learn how to treat Chronic Lyme Disease from people who KNOW HOW! Ask Chronic Lyme sufferers what works for them and talk to the doctors that successfully treat them. Stop calling it Fibromyalgia and saying there is NO CURE.

Puma Of-Thenorth I need to get back to writing my new children's informational & tell all book ~ I Was Bitten By a Bio-Weapon but wanted to take the time to add ~ It is hilarious to see the good doctors at the IDSA continually following the advice or murder Scott Peterson’s mother. “Deny deny deny.”
Yet didn’t Scott Peterson end up in San Quentin?

Maybe when this is all over & done with & the IDSA is exposed for their continued lies they can all be housed in a special jail on Plum Island.

Good old Plum Island remember that place? Just don’t eat the plums!!!

Valerie Mains Wolfer We need to create a public data base of doctors who are continuing to misdiagnose patients, or not diagnose at all, in light of overwhelming clinical evidence. If a physician is not capable of making a clinical diagnosis or refuses to treat in light of overwhelming evidence of disease, they should not be practicing...period! IDSA, You need to do your job and start educating your doctors...you need to stop pandering to a select few of your members who have hidden agendas and obvious conflicts of interest.

Valerie Mains Wolfer Do you think by deleting our comments, our illnesses and stories will somehow no longer exist and disappear? The more you delete and do not respond, the more obvious it is that you're guilty as sin.

Tim Medearis Acknowledge Chronic Lyme Disease and listen to the few doctors who are treating it rather than go after their license to treat. You have ruined many lives with your ignorance and allowed thousands to suffer by your arrogance. Pure evil.

Beth Stormont Thank you for the opportunity to let us express ourselves. Reliable testing and revised treatment guidelines would be a BIG step in the right direction. I think I can speak for the 1600+ responders so far and tell you that we are not happy spending tens of thousands of dollars out of pocket and out of our retirement funds and out of our children's college funds. And how about devoting some big bucks to research? There sure seems to be a lot that's NOT known about tick borne diseases, even among the best doctors and researchers.

I bet just about everyone on this site would be happy to donate blood, or tissue, or whatever it takes in the name of research to ensure our children or grandchildren might one day receive proper testing and treatment. One of my personal wishes is that every camp program and every school nurse be educated about tick borne diseases. I've told all my friends and family how to properly remove a tick and they know to save it for testing, but I can't get to the whole world! Lastly, I would request that Lyme patients to be treated with dignity. I've been dismissed and belittled by some of the best doctors in my city, an eye opening and devastating experience. I am fighting my way back to health and I hope to live long enough to see the changes we are all asking for. Please, do the right thing.

Sara Schultz ...but I WAS diagnosed (very quickly, I might add) with depression and anxiety disorders. When I was finally befridden, unable to swallow food and walk unassisted, I was promptly diagnosed with “Agoraphobia.” (omg??!) And when I refused to take their medications, antidepressants and addictive sedatives, I was told that I was "not addressing" my so-called "health problems"...................

Sara Schultz I would like the IDSA to experience the HELL my mother went though when a doctor told her in 2002 that her daughter was DYING.............

Brenna Short Faulk More CFS, Lyme, Fibromyalgia, and related illness clinical trial in more geographic locations across the country for possible new correlations and information. Not to mention better diagnosis, clarification on illness parameters, and treatments.

Laurie Damsell Fahey I have Gasped for air for SIX HOURS at a time unable to breathe... Only one doctor new what I was talking about he is a Lyme Literate ILADS Doctor.. its called Lyme Disease.. Air Hunger... horrible way to live.

Barbara Mcgill Hello! My name is Barbara McGill. I have been fighting recurring MRSA for the last 13 (going on 14) years and the complications from the infections and the treatment. I contracted MRSA from a piece of equipment that wasn't disinfected properly--I am/was a Critical Care RN. I'm determined to get back to work but have been told I'm permanently disabled. I really want to prove them wrong, but I'm not getting the aggressive treatment I used to get in the beginning. Please give me any advice, Docs', anything to help. I've died to many times, my Primary Dr. (he passed away in 2007)--I threw a PE, outside the hospital and didn't go to the hospital until the next day because my daughter called my surgeon; I had been on Coumadin but even though I was active, I was told that I had a massive clot in my Rt leg and a piece of it broke off and went through my heart, lungs, and brain; I must have a purpose because I'm still here! My primary that passed had friends in the WHO, and told me that if I had to go to timbucktoo, to get better, I would go!!

Please, help!! My e-mail is blm1and2@att.net or you can find me on FB. My employer (The Cleveland Clinic Foundation) has written me off and their lawyers have financially destroyed and devastated me and my daughter.

Karen Hassan I would like to see the IDSA admit that Steere, Wormser, Shapiro, etal. are wrong. I would likethem to admit that the two tier Elyssa, Western Blot test misses almost 60% of the time. It is a shame that they allow a few "bad apples" to make their whole organization look a bunch of idiots. As a patient advocate, my first bit of advice to new Lyme patients is to stay away from ID docs!

Kaethe Mitchell It took 3 1/2 years of progressively worsening illness in my 14 year old daughter, 13 specialists, a hospitalization, and a diagnosis of "she's making up her symptoms" before I happened to pick up a book by the acclaimed author, Amy Tan, called "The Opposite of Fate". Amy Tan has Lyme and something struck a chord: this sounded just like my daughter's story! Had it not been for that book, I don't know if my child would be severely disabled by now, or dead. IDSA, why do we have to do all our own research to find proper care? My daughter had a negative Lyme test early on (because I asked for it, not a doctor), then went on to develop terribly debilitating symptoms over the next few years. Last year she had a SPECT scan of the brain at Columbia University. and it showed severe hypoperfusion of the white matter due to infection. No wonder she had so many symptoms. Thank God she (and now her sister) are under the care of a brilliant ILADS LLMD and are finally getting better.

IDSA, in 2012, I would like to see doing away with the ELISA, bring back the bands eliminated from the Western Blot, and rely on the new blood culture test. I have much more on my wish list, but will settle for these things, if necessary. To read about Amy Tan's battle with Lyme disease and how she finally got diagnosed, go to her website, AmyTan.net and look under "Slyme Disease". (Thank you Amy!)

Kaethe Mitchell Oh, and I live in NY. Plenty of Lyme here and still so many ignorant doctors.

Teresa Shank Why do people think that Lyme disease is all in your head? I have a very dear friend that suffers daily from this debilitating disease. PLEASE, don't let insurance companies say no to the treatment that can cure this disease. This is a deadly disease that afflicts many people and families all over the United States.

Lori Armstrong IDSA please recognize that chronic Lyme is real and that with proper diagnosis and long term treatment we do get better. We need a more accurate western blot that is currently offered!

Susan Spicuzza Gray To see is Lyme, CFS, and XMRV are all connected somehow. We all have the same symptoms with no cure

Stephanie Vandagriff Keep commenting people, let's reach 2,000 comments! IDSA can't stop us.

Sherri Horn Myers My husband was treated for a year and a half for mental illness because the Lyme tests I insisted on came back negative. ID doc said no such thing as Lyme even after Igenix test said positive for Lyme and babesia. I found a Lyme doc in PA who believed in us and started treatment with rocephin. Four months later mental stuff is sooo much better, but it was very bad for a long time with both of us almost ending up dead from his suicidal/homicidal tendencies. Thankfully our insurance pays for the treatments. I wish the medical community would see Lyme as a real illness, an incredibly horrible one, which steals practically everything from its victims.

Phoebe Klemz babesia is the one they are worried about in california because it's in the blood supply. stanford is investigating who got my blood but they could care less about the Lyme and other co-infections that they don't test for. Stephanie Vandagriff it has reached 2000 comments they just keep deleting.

Kim DeSantis Goodwin Two people i know of died this week alone. These are just two i was told of. Young lives one not treated well enough just 4 months of doxy after to many years of being sick. These deaths are your murders. It should say homicide IDSA. if it weren't for your guidelines they would both be with their spouses and children and not in the ground.

Jennifer Schierholt Support better testing for Lyme and its co-infections. As with HIV/AIDS, it is in everyone's best interest to spot Lyme Disease as soon as possible. Timely and accurate diagnostic testing will help many people to avoid needless suffering, and it will help the health care system to minimize expenses. Highly sensitive and accurate testing for Lyme is a win-win for everyone. Please help us this year!

Kaethe Mitchell Speaking of blood supply, I called our local Red Cross (Binghamton, NY) to ask if one can donate blood with a history of Lyme disease. The mamager said Yes, as long as you are finished taking antibiotics and are feeling "well" today. Then I asked her about babesia. She said babesia is found only in the tropics. The donor center asks their potential donors if they have recently traveled to "the tropics', and then proceeds from there with more questions about symptoms. When I told her a simple Google search for babesia yields information that ticks in the US transmit babesia, she was surprised. Oh, and no, they do not test the blood for babesia. IDSA, if my kids donated blood before they were diagnosed by serology for borrelia, babesia, and bartonella, would you be comfortable receiving their blood in the ER, OR, ICU? Someplace in the hospital where you were not conscious and able to refuse a blood transfusion?

Jason Orloff GOT SCIENCE?

Mariann Sawicki Chronic Lyme Disease exists, Elisa test is useless and inaccurate, I have been battling this for years, this is a worldwide epidemic, people are being diagnosed incorrectly and this is a disgrace to society. Stop putting a bandaid on this, what happened to the hippocratic oath.

John Goude When it comes to tick born illnesses Lyme Disease IDSA is one word QUACK.

Carol Hahn Take your heads out of the sand about Lyme disease.

Sarah Conner
http://www.youtube.com/watch?v=VoY7G3Zqwql

Sarah Conner 31 second message to the IDSA

Sarah Conner Dr. Yost saw 2 of the Doctors that wrote the IDSA guidelines

Debbie Sellers Wenger Lets get real about the probability/seriousness/diagnosis/treatment of Lyme Disease. Too many people are suffering needlessly. Admit that it is an epidemic and get new guidelines in place.

Neil Huey Debbie...the CDC says it is epidemic

Andy Lautin I will not repost to this cite. The reason is obvious. I have more important things to write to. A three volume description of neuroanatomy for starters - as a follow up to my treatment of the principle components of the limbic brain. The ISDA's problem is when its colleagues carry an antinosological, antidiagnosis, antitx bias. I entreat any input on the clinical comment rendered by Dr. Gary Wormser.

Mitch Gordon So those of you who are doctors, particularly infectious disease doctors, who read this site -- and are seeing this outpouring from the Lyme patient community -- please reflect on what we collectively are telling you about what this disease has done to our lives and/or the lives of our loved ones, and also what we are telling you about how badly the medical community, worst of all infectious disease doctors, is/are dealing with a huge and quickly growing number of very sick patients. I'm sure you didn't pick this specialty because you wanted to help make lots of people sicker (and financially destitute at the same time). But that's what the leadership of your organization is accomplishing. Is that ok with you? Or can our stories motivate you to take off the blinders and demand that your organization change its course on Lyme into a force for good instead of a force for ignorance and harm?

Stephanie Vandagriff *My father and I have gone 20 years undiagnosed. We now both have perminant damage from the Lyme. My childhood and young adult years have been robbed from me. I'm only 30 years old and I'm now housebound from the disease. Redue your Lyme guidelines. We only get one life on this earth and we want it to count.*

Jason Orloff GOT SCIENCE?#1: This article is one of several that I've seen where investigators validated their new serologic test by carefully looking for the very organism that they are testing for. Many patient and physicians have voiced concerns about the two-tiered test recommended by CDC for Lyme disease diagnosis: How sure can IDSA be of the accuracy of the test for Lyme disease if isolation of the organism is not part of the validation process? Sorry, I tried to highlight the sentence but cannot; for those who made it here but do not want to read the whole article, About halfway through this abstract is the sentence "We necropsied coyotes to determine the adult heartworm infection status" x Vet Parasitol. 2002 Oct 16;109(1-2):45-58.

Validation for use with coyotes (Canis latrans) of a commercially available enzyme-linked immunosorbent assay for Dirofilaria immitis.
Sacks BN, Chomel BB, Kasten RW, Chang CC, Sanders RK, Leterme SD.

Source
Department of Nematology, University of California, One Shields Avenue, Davis, CA 95616, USA. bnsacks@ucdavis.edu

Abstract
Serological tests offer a potentially powerful tool for monitoring parasites in wildlife populations. However, such tests must be validated before using them with target wildlife populations. We evaluated in coyotes (Canis latrans) the performance of a commercially available serological test used to detect canine heartworm (Dirofilaria immitis) in domestic dogs. We obtained 265 coyote carcasses and serological specimens from 54 additional coyotes from several regions of California, USA. We necropsied coyotes to determine the adult heartworm infection status. Blood was collected at necropsy on filter paper strips and allowed to dry; it was later eluted in a buffer solution, and the supernatant was tested for heartworm. Receiver operating characteristic (ROC) analysis was used to assess discriminatory power of the test and indicated a 93% probability that a randomly selected infected coyote would exhibit a higher enzyme-linked immunosorbent assay (ELISA) value than a randomly selected uninfected coyote. We estimated specificity at 96% (95% CI: 92-98%) for 165 uninfected coyotes and sensitivity at 85% (77-91%) for 100 infected coyotes, results similar to published values for the commercial serological test used with dog serum or plasma. Test performance was similar for filter paper specimens and supernatant of frozen whole blood collected in EDTA tubes (i.e.

hemolyzed plasma). We found no difference in test performance among geographic or demographic coyote groups. Our findings support application of the test to filter paper or standard serological specimens for detection of heartworm in coyote populations.
PMID: 12383624 [PubMed - indexed for MEDLINE]

Susan Campbell Chris Finkle
http://www.cdc.gov/ncidod/dvrd/spb/mnpages/dispages/TBE.htm

Stephanie Vandagriff Lyme disease pettition. But keep posting on here, we need to be heard
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-Lyme-disease

Brittany Goff I really wish the IDSA could see what murders they are... how does it feel to kill all the people with Lyme by ignoring it? Do you sleep well at night?

Stephanie Vandagriff OK IDSA. I'm going to keep reposting my story until you stop deleting it. By the facebbok guidelines there was nothing wrong with it for you to delete yet again.

Michael Brookins Get help for the folks with LYME...Come up with a cure for LYME...get our leaders involved....get research on LYME...treat LYME like we treated HIV.....

Stephanie Vandagriff My father and I have gone 20 years undiagnosed. We now both have perminant damage from the Lyme. My childhood and young adult years have been robbed from me. I'm only 30 years old and I'm now housebound from the disease. Redue your Lyme guidelines. We only get one life on this earth and we want it to count.

Diane J. Marie When you type www.ilads.org their logo pops up in posts!

Bernadette Durham Honestly, if I had never gone through three painful years of being told I was anorexic, depressed and suffered with anxiety before running simple (cdc) blood test, I'd never believe doctors could say this to someone so sick and in need of medical help. Truth is, I think money behind this... Insurance companies and govt -- the other problem is no pharma has drug to push for it on flip side. It's a mess and it's not an idsa vs ilad contest here-- it's a need to join forces and start researching this epidemic. Please help & here is my story from SELF MAG (wormser is in it)
http://www.msnbc.msn.com/id//ns/health-infectious_diseases/t/under-the-radar-tick-diseases-spreading-across-us/#.Twj-j_FmSM

Joni Boyd These are the "faces" of chronic Lyme. . . . Each has a name, each has a story. . . Please don't ignore these cries. . . .

Diane J. Marie When you type www.ilads.org in your post, the ILADS logo pops up in your post!
Expand Preview

Sarah Jean Something I wrote to a friend of mine, whose husband is a resident physician:

If your husband wants to make BIG $$$ as a doctor, he should focus on Lyme disease (become what is known as a Lyme Literate Medical Doctor), and move to California (one of the few states where Lyme docs are able to practice without the IDSA threatening to take away their license (following certain protocols of course).

He wouldn't even have to deal with taking insurance, because most insurance companies refuse to pay for most long term Lyme treatment. My Lyme doc gets $350+ for a 30 minute appointment...

It's a super controversial topic in the medical community though. ILADS (International Lyme and Associated Diseases Society) is at one extreme end of the treatment spectrum, and IDSA is at the other. For example, IDSA believes that Lyme can't exist in northern CA, yet the CDC has determined that northern CA is endemic with ticks carrying Lyme (and other infectious diseases). The IDSA also believes that Lyme shouldn't be treated with long term antibiotics, yet they treat Whipples Disease with at least two years of antibiotics. Chronic ear infections are treated with long term antibiotics, and some acne cases are treated with years of antibiotics... which negates their very own stance, that no one should ever be treated with long term antibiotics.

I was one of the lucky few who only had to see three doctors before being diagnosed with Lyme (others see dozens or 100s of clueless doctors before getting help). I also am lucky enough to have responded well to long term antibiotics. I was on abx for only two years and I feel fantastic overall, with only minor muscle and joint pain left over. Other people I know have been misdiagnosed with ALS, MS, CF, etc., when they actually had Lyme... then they were treated with long term antibiotics, and now they are healthy again.

I heard that your husband wants to focus on family medicine... but, often the first doctor a person with Lyme sees is a regular family physician. The Elisa and Western Blot (WB) tests are notoriously inaccurate, yielding many false negative results. Lyme is supposed to be a clinical diagnosis, but most doctors don't realize this, and rely solely on the Elisa and WB. If your husband was to do some extra training with a LLMD he could prevent many cases of Lyme from becoming what is known as Late Stage or Chronic Lyme.

Obviously this is a huge issue for me... and I can't stand that new doctors are being trained by professors that are either afraid of the IDSA, or they don't look at things rationally/logically.

One doctor at a university in Kansas says that:

#1-there is no Lyme in Kansas (what, do ticks think that they can't exist in other cities, states, countries? People travel, animals travel. Ridiculous!)

#2-that people should only be treated if they live in an endemic area. The problem with that though is that a place doesn't have to be "endemic" to have Lyme carrying ticks, and people and animals travel! What if a person got Lyme in another city or state? What if a persons pet moved with a family to a new city/state and carried ticks on it that had Lyme? Illogical teaching is being done by some of these institutions.

Basically, Lyme treatment is where the money is. Your husband would probably have to turn patients away or put them on a waiting list, and wouldn't have to be shafted by Medicare prices or low negotiated insurance rates in order to practice medicine...

Kathleen Dickson REPORT YOURSELVES TO THE FBI FOR BEING MASS-MURDERERS!
http://groups.google.com/group/sci.med.diseases.Lyme/browse_thread/thread/05908f369a336ecf?hl=en#
EU Hysteria: Hold on - SmithKline owns the proprietary Antibiotic-Resistance data. - sci.med.disea
groups.google.com
Hold on, now. SmithKline bought Corixa which acquired a 11.5 million dollar b...

Kathleen Dickson IDSA has no integrity, so I wonder why everyone here bothers to complain to such mass-murdering crooks. http://www.actionLyme.org/120102; Lamestream News (WaPo) reports that Lyme and LYMErix are immunosuppressive.
www.actionLyme.org
Make a TLR agonist bot so we can do away with ticks-and-fungal- immune suppresseion.

Stephanie Vandagriff Although change would be great, we post to be heard and to express ourselves, which were usaully not able to do Kathleen. Post your story, so they know what they did.

Susan Campbell Chris Finkle I know that somewhere I came across one of the Doctors (who did not have any $$ conflict) that was on the panel for the Lyme Guidelines speak and advise that when the panel was requested to hurry along in order to get the guidelines in place and approved, there had been no time to discuss chronic Lyme at all and they just submitted the guidelines for approval without any discussion about CHRONIC Lyme. - did I see this in the "Under Our Skin" documentary? or maybe on a you tube upload? I just cannot remember. Shouldn't the /notes/ documents? of the "Guideline" Panel Discussions be put out for review - challenged???

Stephanie Vandagriff It waas on Under Our Skin. They interviewed him.

Diane J. Marie The IDSA Lyme guidelines panel members and the rigged July '09 hearing IDSA members are murderers and they are attempted murderers. They belong in prison (except Sam Donta.)

Diane J. Marie www.ilads.org

Cheryl Monahan Please change the Guidelines for Proper Treatment & Accurate Testing & Educate the doctors. Please do thee right thing for the people suffering that do not have any idea what has happened to them. If I had proper treatment I would not have almost lost my life. I'm fighting this disease right now & it's not pleasant. I have a family, just like you, that had to watch me suffer & still does. I don't like my family watching their strong role model become so weak. It's not fair. The only Fair thing to do is to make it right & help the people with Lyme disease & co infections. We are not looking for money, just our health & the prevention that this does not happen to our love one or possible someone you may care about. Prevention with

Accurate Testing & the Proper Treatment to start will be such a help.

Troy Vincent Sometime in 2007 or 08,the bullseye rash appeared,did'nt know what it was.By Sept 2010,the chronic fatigue,inflamed tendons and joints, burning eyes, sensetivity to light and sound set in and i could BARELY move my arms.After being referred to an ortho surgeon for shoulder injury,(and being told there was none,but given a quartizone shot anyways) my primary doc ran the Lyme test.2 bands pos.on Lyme anti-body,2 bands pos.on Western Blot, in Feb.2011 i was given 30 day run of Doxycyclene,refered to rheumatoloist,who said,and i quote,"You don't have Lyme disease, you have a footprint of possibly having it in the past." Nothing further was done,by any body.September 2011 the rash returned,and my symptoms are all but back in full force.Tuesday 1-10-2012, I finally get to see a ID doc.Hopefully things can go forward from here, armed with the knowledge i've gained from these post, thank you.

Susan Campbell Chris Finkle IDSALymeDiseaseFinalReport http://www.idsociety.org/uploadedFiles/IDSA/Topics_of_Interest/Lyme_Disease/IDSALymeDiseaseFinalReport.pdf

Jen Jasper @Susan Campbell Chris Finkle -- I think the doctor was Sam Donta.

Tiffany Gonzalez IDSA - I'd like you to take each one of these comments and Lyme Disease seriously... YOU asked the question... so now I ask, WHAT are YOU going to do about it??? I've had to leave this country 3 times to get treatments for this disease because YOU guys have not done anything to help. Really? Is that how you guys want it, for your own country to have to leave for proper care? Sad, but don't worry, you aren't holding me back. I'll leave again, and give my money to another country rather than the good old USA if I have to. I am my own advocate.

Alyssa Ryvers *I'd like the IDSA to repay me for lost wages; the house I sold; the two cars...to demonstrate remorse for releasing Lyme disease guidelines that are underscored by corruption . . .*

Billiejo Miller Rush *Right the Wrongs You have Created By Unreliable testing and Wrong Lyme Disease treatment guidelines!!! You are Killing People Slowly.*

Denise Weaver Since the time of your posting, I have...slept, took medicine, been dizzy, took a detox bath and in the bathroom with diahrea from my medicine...i suffer from chronic lyme...now....please tell me how your weekend has been since this posting.....TY

Tiffany Gonzalez P.S. I'm in a suburb of Chicago... But Lyme doesn't exist here right? Please change the ELISA test to something more accurate at doctors offices. Most of my 20's have been wasted away by being sick. I've missed out on so much life. Now I've entered my 30's still sick and sitting on the "sidelines" while my friends & family go on dates, get married, have kids live the dreams I had. Instead I sit online watching pictures of them and knowing I'll never be able to have that, and not even have a child because I'm too sick to care for it, and wouldn't want to pass on this disease and infections to them.

Linda Laidlaw I would like to see the ID doctors, like those who failed to diagnose my daughter when her Lyme disease might have been easily treated, recognize that tick-borne illness might be a part of differential diagnoses when nothing else seems to be the cause of debilitating illness. My four year old daughter, after being a normal child, became so ill that the only option for her seemed to be institutionalization (since the medical profession could diagnose nothing but what they called an 'untreatable, unknown, neurodegenerative illness'). When 'miraculously' she began to get better after starting treatment for tick-borne illnesses, the same pediatric IDs, who although admitted, 'the treatment seems to be working' still refused to name her disease and got in the way of treatment she might have received by her pediatrician. I think it's time to stop relying on studies that seem to provide 'tunnel vision' and start listening to and watching patients. How can it make sense to let a four year old decline to that degree? How can it make sense to fail to treat, even when treatment is clearly turning around a condition that everyone said would be fatal? I hope -- for all those children who might suffer like my child -- to see a major IDSA paradigm change.

Denise Weaver oh...I forgot....I also keep a plastic bag in a garbage can next to me in case I must ralph......Thank you for caring enough to ask and i look forward to your reply on Monday.....oh...you know what else....I have worked with child abuse for the past 33 years...I am very proud of the children whose lives I have saved......yes SAVED...but with LYME I have been unable to work for the past 18 months......amongst these comments from Lyme patients, you will find policemen, nurses, church leaders....all of us would give our eye tooth to go to work on Monday, as you are able to do.....your policies have rendered us incapable of helping society....of children becoming educated......i would please like you to consider the cumulative affects of your ineffective and brutal policies...one of us may get better and save your life one day

Denise Weaver we would like to hear the TRUTH from you.....oh my...you need all the prayers you can get

Alyssa Ryvers I'd like the IDSA to repay me for lost wages; the house I sold; the two cars...to demonstrate remorse for releasing Lyme disease guidelines that are underscored by corruption: http://www.youtube.com/watch?v=XPGW4BnlE7Q&feature=player_embedded

Ingrid Boutilier McAdam See, we are just hoping that one of you, any one of you, finds your moral compass and/or a conscious...HIGHLY UNLIKELY !! Kudos to a great open-ended question, tho! ;)

Janice Mattoon Miller Awareness of chronic Lyme disease. It should no longer be ignored

Billiejo Miller Rush Right the Wrongs You have Created By Unreliable testing and Wrong Lyme Disease treatment guidelines!!! You are Killing People Slowly...

Michelle McKeon I suffer from a particularly vicious episode of Lyme Encephalitis. I have been sick for over five years and have been told by doctors that I suffer from one of the worst cases they have ever encountered. It is due to the low-profile of Lyme Disease in this country that I struggle to receive the proper care that I need. My story is not unique; my plight mirrors that of thousands of other Lyme victims in the States. Many studies suggest that one-third of Lyme Disease patients continue to show chronic symptoms after undergoing an antibiotic treatment, yet the Infectious Diseases Society of America (IDSA) and the US Centers for Disease Control (CDC) do not recognize Lyme as a chronic illness. Lyme Disease research - though it has come a great distance from its inception when the Disease was discovered in the 1970s - remains in its infancy. Currently, due to the status of Lyme as a temporary illness, long-term sufferers often slip through the holes in our health care and disability systems. Many with Chronic Lyme, like myself, were forced to quit their jobs when they became too ill to work. Unable to go on Disability, it has become increasingly difficult to pay medical bills, especially because most Lyme doctors cannot provide care under health insurance. IDSA please open up your eyes and change your guidelines. Lyme Disease is an epidemic, it is not going anywhere, and it is destroying my life as well as many others.

Lisa Koch Hanmer Absolutely need to recognize Lyme disease!!!! It can no longer be ignored. It is having a significant impact.

Wendy Vogt Seriously? You are deleting thousands of posts. Mine are gone from yesterday. Your organization should stand for more than I Don't See Anything. 2012 is predicted to be a record year for ticks so you will have to deal with this. It's not going away no matter how many posts you delete or victims you ignore.

Brienna Reed Why are you deleting posts, IDSA, like Wendy says " We will NOT be ignored" The Lyme disease coverup will be uncovered!! It is an epidemic, we will get help, and you can start by listening!

Laney Rather I would like to see doctors not being punished for truly trying to help their Lyme patients just because it "doesn't follow guidelines". Guidelines are there to suggest a path that could help; but, each person is an individiual and needs individual treatment.

Five members of my family (including myself) tested positive for Lyme disease SIX years ago, and still have not been able to receive adequate treatment. Not only that, it took THREE years to get a Lyme diagnosis. From the time I was 12 (I am 21 now), I have gone through varying stages of illness. It has ranged from mild in severity-- in the early stages-- to disability. I haven't been able to have a single job because of this disease, and both of my parents are disabled.

This disease is spreading so quickly and destroying so many lives. I pray that few people will have to suffer in the future because of the unwillingness to acknowledge Lyme.

Mariann Sawicki God bless all Lyme sufferers, I know and have Faith that we will soon get the attention and proper care, there are far too many of us out there. Each of us has a different story but it is all the same, why should we have to wait till someone prominent has it before something is done, what happened to the hippocratic oath??????

Karla Williams Your own founder of the IDSA Dr Waisbren, does not agree with the guidelines you put out. You should be ashamed of yourselves. You are responsible for the suffering and deaths of people that can not get help from insurance companies and who suffer from Chronic Lyme Disease. God will punish you and yours. The sins of the father will be visited on the sons and daughters. And you deserve it more than anyone! Any Dr that belongs to your self important society and goes along just to belong deserves what they get.

Peggi Mauney One day, one of you will have a loved one who gets bitten by a tick......it will happen...and you will find it impossible to get medical treatment. You will see your loved one's body and mind start decaying and you won't be able to do anything to help him. It's your fault, too. Feel guilty? Bet that changes your perspectives on treatment guidelines. Please change your guidelines for treating Lyme Disease by having input from reputable LLMDs. Here, on this FB page, you see hundreds of stories posted by people from all walks of life who want to be able to lead normal lives, work at jobs, care for their families, and get medical help. It took us 3 years to get treatment, almost too late. I thought my child was going to die. I did find a doctor after long weeks of research, and I'm getting medicine for my child. BUT - I have to get medicine from another country......where are you, America? WAKE UP, WAKE UP!

Jessica Armstrong Diagnosed 15 years after my tick bite, chronic lyme has changed the course of MY FAMILY's life irreparably. My daughter contacted it in utero. Four years later, after her progression of neurologic complaints culminating in seizures, she is now improving on treatment for tick born illness. Four years into my own treatments, I am finally well enough to put a birthday party together for her. In the meantime, my family has lost our options for growing our family (having more biological children is no longer an option and adoption agencies rejected us based on my health), we have lost all of our savings paying for medical bills, our 'free time' is spent exhausted, advocating, doing medical research and trying new treatment protocols. What can you do? Care enough to make a change. Your myopic guidelines have led to wholesale medical ignorance. I saw eight specialists over the years prior to my diagnosis, none of whom knew enough about chronic lyme to even test for it. I knew nothing then either. I thank God repeatedly for the immunologist who finally looked at my symptom progression over the years and decided to include lyme testing in the barrage of diagnostics. That doctor knew enough to test beyond the ELISA and initial Western Blot results, bc he studied beyond and outside of your blanket definitions for this disease. Please make the madness stop. It would be great if my daughter could know one day that she has completely eradicated this infection from her body, and could have no qualms starting a family of her own.

Carolyn Jasken Many doctors are trained, rather than educated. They know everything there is to know about their field. Their board certified. That means they know everything. Anyone who tells you anything different doesn't know what they're talking about." I want the IDSA to become educated and not trained and start thinking out of the box when it comes to different diseases and treatment. How about instead of a lifetimes worth of antidepressants to treat somatoform disorders (pain is real, but all in your head) for people with lyme, you start diagnosing and educate yourselves on what actually works! Win win!

Dawn Havas What would I like to see? I would like to see the IDSA to start practicing the true art of medicine rather than the pseudo science of the Pharmaceudical Industry control over the Allopath Medical establishment and continued self serving greed.

You have continued to ignore the needs of Lyme Disease Patients as well as the fact that Vaccines have NOT saved millions of lives and have and continue to destroy the natural immunity and health of human beings. Vaccines have NEVER been proven to be safe and cause many more serious chronic health and neurological issues and diseases than the one each is alleged to prevent.

The infectious diseases that vaccine have claimed to have stopped had already been eliminated/declined years prior to the vaccines even being created. Stand up and bring back the initial true purpose of medicine. Start curing the causes rather than just the symptoms.

Stephanie Vandagriff I'm still waiting for a response. You need to do a new post answering everybody's questions. Otherwise this is a big slap in the face. You asked for feedback and we gave it to you. Please have the professional curtesy to respond. If you have enough time to delete comments, then you have enough time to answere them.

Sherri Elsworth Stephanie perfectly stated! See the girl to the left of me she is my 11 year old daughter who was diagnosed with 2nd stage Lyme. I didn't know anything of Lyme until she was diagnosed. We are now in the Lyme game. Our last doctor we saw who is a neurologist in Rosville, CA point blank told me Lyme is very uncommon in California and the blood test are very inaccurate. We were seeing him to see if she had Nero Lyme. He was basically telling us how for sure do we know she has Lyme. I can't believe it, it really is true the political game that is played with our kids precious lives. Please Please IDSA have a heart and not the love of money change your guide lines and educate properly about Lyme and treatment needed. Some of us can't afford to see Lyme Specialist so our kids suffer all because of money and selfish gain of a Political Lyme game that is played with our kids lives.

Joël Ruhlmann I need an effective cure for my seronegative chronic Lyme ! IDSA could begin this year by recognizing that chronic Lyme disease really EXISTS !

Renee Biondo Vredevoogd help with us chronic cases of Lyme that had 1-2 weeks of antibiotics back in 1990's and have had symptoms return (cannot work now and I loved my work as a rehabilitation counselor- stress was my trigger). Have nuero Lyme now.

Karla Lehtonen Dear IDSA and all chronic Lyme patients,

Please pay close attention to one of the most important new developments in Lyme disease testing which is the introduction of the first commercially available Borellia culture from Advanced Laboratories in Sharon Hill PA. Initial studies have shown that 80% of Lyme patients who are symptomatic and that have not been on antibiotics for at least a month will test positive. This test has the potential to turn the entire chronic Lyme controversy on its head. It will allow many patients who are still symptomatic after antibiotic treatments to prove that they are still infected and that further antibiotic treatment is warranted.

For the initial press release:
http://www.lymedisease.org/news/lyme_disease_views/newlymetest.html
For the most recent press release:
http://www.advanced-lab.com/news/borrelia_culture_update.phpExpand Preview

Scott Reed Thursday at 9:47 a.m. the IDSA responded to us "IDSA wants to encourage open dialog...IDSA takes Lyme disease very seriously, for more information visit: http://www.idsociety.org/Lyme"

This link takes the reader to the IDSA Lyme page with a link to the "Ten Facts You Should Know About Lyme Disease".
OK, lets have an open dialog:

IDSA fact #1:Lyme disease is caused by bacteria called Borrelia burgdorferi that is only transmitted to humans when they are bitten by an infected tick.

DIALOG RESPONSE: There are many documented cases of Borrelia burgdorferi being transmitted in utero, and many more have told you this in their posts.

In 1986, Weber reported a case of Lyme infection in a newborn baby. The mother had been bitten by multiple ticks during her first trimester. She developed an EM rash several weeks later. She was treated with a “standard” course of oral penicillin for seven days, three times a day. The baby was delivered at term and appeared normal. During the next 23 hours the baby developed breathing problems and died. Autopsy showed brain hemorrhages. Spirochetes compatible with Borrelia burgdorferi, the Lyme spirochete, were demonstrated in the brain and the liver. Initial testing of the mother’s blood was negative for antibodies to the Lyme spirochete; however, at a later date her frozen blood tested positive for IgM antibodies by the ELISA test.

Markowitz published a study of Lyme and pregnancy in 1986. He described nineteen patients who were infected during pregnancy. Five of these had adverse outcomes (one fetal death at 20 weeks, high bilirubin level in a four-week premature baby, webbed toes, blindness and developmental delay, and a newborn rash). Thirteen of the nineteen had received antibiotics. The authors concluded that there was no proof that Lyme was responsible for the adverse outcomes since all of them were dissimilar. However, there was a consensus that this was an abnormally high frequency of adverse outcomes, and that pregnant women with diagnosed Lyme should be treated immediately with penicillin.

Williams and colleagues conducted a study in a Lyme-endemic area in New York of umbilical cord blood. Of 255 infants tested, 10.2% had detectable antibody to the Lyme spirochete. Of 166 infants born in a non-endemic area, 2.4% had detectable antibodies. The rate of birth defects did not differ significantly between the two groups; however, the first group tended to be of lower birth weight and smaller for their gestational age, and tended to have more jaundice. The authors concluded that these differences were not significantly different. A glaring flaw in this study is that it only included live births. Since miscarriages, stillbirth and perinatal infant deaths were not included, the possibility of congenital defects possibly associated with Lyme and incompatible with life are not included. Therefore, the author's contention that no association exists between gestational Lyme and congenital defects should be viewed with skepticism.

From the CDC website "Although no cases of Lyme disease have been linked to blood transfusion, scientists have found that the Lyme disease bacteria can live in blood that is stored for donation. Individuals being treated for Lyme disease with an antibiotic should not donate blood."

Overwhelming studies and research confirm that IDSA FACT #1 is false.

IDSA fact #2: 2.To infect its host, a tick typically must be attached to the skin for at least 36 hours.

DIALOG RESPONSE: The data suggests this is not true. Studies that looked at improper removal of a tick showed much shorter attachments are possible. In several mammal studies in the late 1980s, it was shown in many species including dogs that within hours of tick attachment that the Lyme organism is with every beat of the heart circulating through the entire body. The spirochete's motility allows it to position itself into the cracks and folds of a blood vessel wall. Borrelia burgdorferi has a tropism or an attraction to attach to the endothelial cells lining blood vessels. Within 24 - 48 hours the blood- brain barrier has already broken down and the infection is potentially already established within the brain. (1989 Immunological Methods of Borreliosis Cold Spring Harbor)

Overwhelming studies and research confirm that IDSA FACT #2 is false.

IDSA fact #5: Anyone who has symptoms for longer than six weeks and who has never been treated with antibiotics is unlikely to have Lyme disease if the blood test is negative.

DIALOG RESPONSE: Borrelia bacteria are genetically equipped to change their antigenic appearance. There are well over 1000 Borrelia isolates of Borrelia burgdorferi that are strain variations in the USA alone. The strain used in the blood test B-31, is never found in nature, and when B-31 tests were compared and tested by independent researchers in Madison WI, France, Austria, and United Kingdom, B-31 had short comings and never had the essential antibody detection that the tests developed from local wild-strains produced.

And as mentioned in the previous response dialog once Borrelia bacteria breach the brain's defenses, absolutely no Lyme serology test short of an autopsy can rule out infection within the human brain.
And there are many other well known problems with the current test for Borrelia. The fact that so many have posted with a disease that "doesn't exist" also proves IDSA fact #5 is also false.

IDSA fact #6: Most cases of Lyme disease are successfully treated with a few weeks of antibiotics. Using antibiotics for a very long time (months or years) does not offer superior results and in fact can be dangerous, because it can cause potentially fatal complications.

DIALOG RESPONSE: In his testimony before the Joint Massachusetts Legislative Committee on Public Health, ILADS President DR. Cameron stated "...in 2000 when Drs. Wormser, Steere and others concluded that "chronic Lyme disease does not exist as a distinct entity." The guidelines were adopted by the Infectious Disease Society of America (IDSA). Despite 35 years of research and thousands of Lyme disease patients described, the IDSA concluded that "chronic Lyme disease does not exist as a distinct entity.
Why is this relevant? In 1977 Dr. Steere believed antibiotics were ineffective (Steere AC et al: Annals of Internal Medicine 86, 685 (1977). Because of this belief many patients like Carol Goodman suffered and got worse. It wasn't until the early 1980's that Dr. Steere realized what other doctors treating Lyme already knew

that antibiotics frequently worked (Steere AC et al: NEJM 312, 869 (1985).

There are thousands of documented cases and many posts to you, IDSA members, that back up the fact that a majority of Lyme cases are not successfully treated with a few weeks of antibiotics and those that seem to be frequently relapse after the treatment has ended. Some of Dr Steere's own success story patients have related the failures of "a few weeks of antibiotics". This unfounded and mistaken view of a few IDSA doctors is once again causing pain and suffering to thousands while making treatment options expensive and few.

IDSA fact #6 is false and the current guidelines need to be revoked.

You (IDSA) asked for an open dialog. Please, I respectfully beg of you to listen to the voice of the suffering. Show compassion to the many who have struggled with the social, the economical, and the emotional battles of this disease. Do what is right, help them and future generations by revoking your guidelines, help further educate your doctors and the public about this debilitating disease.

Thank you,
Robert S. Reed
Father of a 19 year old daughter, bedridden with Chronic Lyme Disease

Lori Ditzler Hagarman Where is your soul and where is your conscience???? People are sick and dying and you are partly responsible!

Harda Wagner I am not affected by Lyme disease myself but many of my friends are. Right this moment a dear friend, 33 years of age, suffering since 12 years from late stage chronic neurologic lyme disease, is on the plane to a country far away from Germany, his very last chance and hope, because in Germany no doctor can help him. I am praying he will survive the flight - and I am asking you from IDSA - WHY is it possible to reach this stage ?

Also I would like to know, you from IDSA as well as from your family members - will you also stop treatment after 3 weeks with Doxycycline after having a tick bite ? I hope you read each single posting on this wall and take necessary action - however not in 2012, not TOMORROW - but, please, please... STILL TODAY ! Each single day passing is too much for millions of sick people.

Beate Scholl What I would like to see from the IDSA this year, is that you no longer ignore patients with chronic Lyme Disease and start admitting that a chronic persistent LB infection exists. Haven't you sworn the Hippocratic oath "First do no harm"? Lyme has taken my future, 23 years ago. Maybe Lyme does not kill, but it takes the lives of hundreds of thousands. I'm living in Germany where Lyme Borreliosis (LB) is highly endemic, and because of your outdated guidelines patients struggle hard to find proper diagnosis and treatment. Please find an answer for chronic LB.

Jean Hemond According to Dr Eva Sapi research group standard Doxy for one month reverts spirochetes to Cyst and L forms. My own 25 years with this disease and the experience of thousands of LD patients suffers from your biased guidelines themselves that are the main factor in inducing chronic Lyme disease.

Donna Zukaitis Falcone My heart breaks reading these.

Carl Tuttle Please read the letter below addressed to Professor Armin Alaedini, corresponding author of the Lyme disease study: “Anti-Borrelia burgdorferi Antibody Profile in Post-Lyme Disease Syndrome” http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3122515/

University Medical Center,
1130 Saint Nicholas Ave., Room 937,
New York, NY 10032.

Dear Professor Alaedini,

Please refer to the following excerpt from your study:

“Significantly higher antibody reactivity toward the p31 band on WB and toward the recombinant OspA protein on ELISA in the PLDS group, may be indicative of a longer-than-assumed course of active infection in affected patients.”

This may have been caused by a delay in the start of the appropriate course of antibiotic treatment and/or an undocumented repeat infection(s) in many PLDS patients. This finding would be in line with previous studies indicating that delayed treatment is associated with increased post-Lyme disease symptoms (20).”

I chased an unresolved fatigue for twelve years before diagnosed with late stage Lyme in the fall of 2008. Exhaustion was so profound that I was evaluated for a possible mitochondrial disease per the attached clinical note from Dr Mark Korson, Tufts Medical Center's Metabolic Clinic
http://home.comcast.net/~runagain/Dr%20Korson%20Summary.pdf

Objective evidence of serious disease included high elevations of carbon dioxide
in blood,
http://home.comcast.net/~runagain/Arterial%20Venous%20Blood%20Gasses.pdf

Cardiopulmonary Exercise Test reviled low MAX O2 consumption due to cardiovascular limitation
http://home.comcast.net/~runagain/CardioPulmonary%20Exercise%20Test%20Results.pdf

and amino acid deficiencies in sixteen out of twenty one tested.
http://home.comcast.net/~runagain/Amino%20Acid%20Lab%20Results.pdf

These are specialty tests most Lyme patients will never experience. At that time I was totally disabled and on oxygen

I did not see measurable improvement from antibiotics for sixteen months and was bedridden with Herx reaction for the first three while on Biaxin and Plaquenil. I experienced a four month Herx from Doxycycline which provoked severe joint pain requiring Vicodin for pain relief as Motrin provided no benefit. Herxheimer was also experienced with Bicillin LA injections and Rifampin. I continue to have bouts of exhaustion which require rest but I now recover more quickly.
All family members are being treated for Lyme disease and were featured on New Hampshire Chronicle's "Living with Lyme" ; New Hampshire's Growing Epidemic.
http://www.wmur.com/chronicle/24181311/detail.html
Our story is not unique as the majority of patients debilitated by Lyme missed the narrow window of opportunity for successful short term treatment. The disabling symptoms are not the "daily aches and pains of living" as your colleague Gary Wormser believes while wasting taxpayer's dollars funding his study "SUBJECTIVE SYMPTOMS AFTER TREATMENT OF LYME DISEASE" The petition against this study has gathered signatures from across the US, Canada, UK, Ireland, Belgium, France, and the Netherlands. Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-lyme-disease

Advanced Laboratory Services' Borrellia culture test has proven that persistent infection or chronic Lyme does in fact exist because a direct culture identifies the actual bacteria not antibodies to the infection.
http://www.wmur.com/chronicle/24181311/detail.html

I received authoritative communication from within the laboratory that the lab is seeing positive cultures in 80% of symptomatic post treatment Lyme patient specimens. These results have come after hundreds of tests.

Best Regards,

Carl Tuttle
Hudson, NH 03051
Website: New Hampshire Lyme Misdiagnosis
http://home.comcast.net/~runagain/site/?%2Fhome%2F

LeighAnn Raney Tuck Open your eyes and see what this disease is doing to us! Have had this and the coinfections for over ten years! No insurance will cover MD's that know what we need to survive!!

Michelle Murphy According to microbiologist Tom Grier, (who was dx'd w/ MS then Lyme),"For a spirochete like Borrelia that is a slow divider (24 hrs under good conditions) to get the same lethal exposure during cell-wall synthesis as say treating strep bacteria, you would have to treat for one year and 5 months." Nevermind the other forms the spirochete makes." Just one brain autopsy that finds spirochetes post antibiotic treatment, can disprove the misguided position that a few weeks of antibiotics is sufficient to "cure" Lyme Disease, and that work has already begun." Dr. Andrew Pachner, Neurologist , infected mice w/ B. burgdorfeeri and one month later extracted the surviving bacteria from the blood and from the brains of the infected mice. What he found was basically that the bacteria in the brain, over the course of several divisions, changed radically from the bacteria that he started with and injected into the mouse's peripheral blood.The spirochetes isolated from the mouse brain now expressed a new set of genes. The brain-strain bacteria were isolated from the immune system and appeared to be a new isolate with new and different surface proteins." This is a very"smart" pathogen . why are you not taking this seriously? What is in it for you to withold treatment for countless symptomatic patients? Ego? Greed? " Who has signed their guidelines in the blood of dying lyme patients?"

Del Carmen No surprise. Having worked in the medical society for XX PLUS years, have personally witnessed the waste and CORRUPTNESS which truly exists. And for what? The ALMIGHTY DOLLAR. And for WHOM? The suffering of HUMAN BEINGS. DISGUSTING! I am THOROUGHLY not only disgusted but feel a great deal of anger and sadness of what prevails. Of that which is being swept under the table. At the amount of b.s. which occurs. I am SORRY for all of you who are SUFFERING due to what has become a system NONE OF US MAY TRULY TRUST IN. XO
~Del.

Sarah Ruminski REVISE YOUR GUIDELINES. How many millions of us have to suffer and either die or want to because of financial/political corruption? This is NOT a cut and dry dx. THIS IS A CLINICAL DX. Waking up every morning and fighting for my life is difficult enough; being denied treatment based on the recommendations of IDSA (which Medco just did to me) is depolorable; if I had cancer I'd be on the nightly news. Do. The. Right. Thing.

Denise Weaver *P.S.....please stop deleting posts...that is just disgusting...how dare you delete the posts of folks reaching out for help....gosh, I hope no one ever deletes your lifeline.*

Denise Weaver *there are many folks who have kept track of every single post....if yours differ, you will have some explaining to do to the public.*

Monika Krajka L.Y.M.E. how can you people still ignore it?!

Lyme Pixie Having been misdiagnosed for over 30 yrs, I lay here wondering where do I start. How about teaching infectious disease Drs how to look at blood, read labs, and to look outside the CDC guidelines. I was turned away by two prominent infectious disease with a positive lyme and several co infections. When i insisted on being treated for babesiosis , they both refused. Both Drs stated " they do not treat chronic Lyme". Why? I can send you a timeline of misdiagnosis, hospitalizations, medications that hurt my immune system. Methotrexate, steroids, pain pills, vioxx. All masking my true diagnosis. Not one of the 100s Dr ever asked me about tick bites, or my septecemia of unknown origin. Please understand the damage is costly and the generations to come should not have to suffer. Mandatory training every 2 yrs for every infectious disease Dr on Lyme and co infections, similar to HIV /AIDS mandatory training required by very health care professional. We are the new AIDS....and we are suffering needlessly. Please don't let another Lyme patient die on your watch.

Susan Larsen I would like to see the IDSA become a world leader in the treatment and cure for lyme disease. The world is watching. Let's put the past behind us and show everyone what America can do.

Aoife Ryan I would like IDSA to help all the sufferers of lyme disease world wide, by recognising that Chronic lyme disease exists and facilitating doctors to treat it. Too many people are suffering needlessly. Lives have been, and continue to be ruined. Please STOP IT NOW

Nancy Kargel IDSA - I hope that the reason my post was deleted is because you read it, recorded what I wrote, so you didn't need it anymore...

Holley Ucantspellitanyway I'm 27+ years chronic with Lyme, Babesia, Bartonella & Anaplasma. I'm only 39! 67 medical professionals & MDs in 14 years & I was not diagnosed correctly until 2009. I NEED...We ALL NEED you to stop hiding your heads in the sand, acknowledge the truths of the nightmares we are living AND let us EDUCATE YOU & the rest of our society so we can control this epidemic. We must all work together to stop this suffering! You are not my enemy. I am surrounding you all with light and I am praying for your enlightenment. We can do this together!

Denise Weaver Sunday...did you get to go to Chuch,maybe out for dinner,atrip to the park or mall, make a huge Sunday dinner,take the dog for a walk,play with your children...we did not.....shame on you. Many of these folks today are staying by their childrens bedside, staying in their PJ's, too weak to move...May I suggest you visit us...you are more than welcome to come to my home, read my Lyme records from the past 10 years, look at pictures of me and read my resume and job experience prior to getting this disease.

Nicole Randazzo Long Island is a known endemic area and not one of the 20 doctors I saw 2 years after my tick bite would treat me. There isn't 1 doctor on all of Long Island who treats properly with combo antibiotic for long term. Not one of the hospitals in Long Island acknowledge or treat for Lyme and all because they are afraid if they do they will be involved in a lawsuit and loose their license to practice medicine. So in case you were wondering if your struggles to find a doctor had something to do with where you lived, it doesn't.

Denise Weaver P>S>.....please stop deleting posts...that is just disgusting...how dare you delete the posts of folks reaching out for help....gosh, I hope no one ever deletes your lifeline.

Denise Weaver there are many folks who have kept track of every single post....if yours differ, you will have some explaining to do to the public

Sheryl Hotlen Rivett I'd like to see current research and attention to the vast number of people in this country who don't discover they have Lyme Disease until it is late-stage, disseminated and in their central nervous systems and brains. Your guidelines are inadequate, research inadequate, and understanding of this population of patients unfortunate. "Chronic Lyme" has become a catch-all label that is not specific enough and that ignores the complex of symptoms that grow in complexity when physicians don't accurately diagnose Lyme in its early stages. Please call it what it is: late-stage, disseminated, and MOVE ON! Move on to research, intelligent answers, and honor the many patient narratives that are out there. The truth lies in the narrative. And in the clinical knowledge of the brave physicians who treat this population.

Christel Manson As you have read, Lyme is seriously impacting many of our lives. Please open your mind and your hearts to see that this isn't a fake disease. Real people are having really bad problems. I have spent a small fortune on attempting to get pregnant, having a child born with a seizure disorder, and then my own health failing due to Lyme Disease. Futher, the two later incidents wouldn't have occured had I NOT had lyme disease. All I want is to go back to the life I previously had. You hold so much power in helping the world see that Lyme is real, and people do suffer from this. We are not crazy..... I pray you will hear the cries of us, and take the time to constructively review our issue! HIV and Fibromyalgia use to be "fake" illnesses also..... you can change this, and make all of our lives so much easier. Thank you for your time!

Melanie Gaulke Saltzman Thank you for asking! I would like to see more lyme literate doctors. Especially the ID docs. They told me the first time I saw them they tested me for AIDS. Then RA and on it went. Time was ticking by and I was getting worse. I finally got in to see the 'specialist' in the infectious disease department at one of the largest university based hopitals in Ohio.

Melanie Gaulke Saltzman I was treated quite rudely, he beliitled me and my situation and then concluded by exclaiming that chronic lyme is not real and therefore I need to seek help from somebody else!

Melanie Gaulke Saltzman Also, the first ID doc said that lyme disease does not exist in Ohio! WRONGO!

Nicole Randazzo WHEN IS THE IDSA,THE ENTIRE MEDICAL COMMUNITY AND THE US GOVERNMENT GOING TO ACKNOWLEDGE THAT THE BACTERIAS THAT CAUSES LYME AND ASSOCIATED CO-INFECTIONS IN OUR BODIES IS THE BACTERIA THAT THE WORLD HAS BEEN WARNED ABOUT? THESE BACTERIA ARE HARD TO DETECT WITH HUNDREDS OF SPECIES, CHANGES TO AT LEAST FIVE KNOWN FORMS, IS CAUSING MANY OF THE KNOWN AUTOIMMUNE DISEASES WHICH HAVE NO CURES AND ONLY EXPENSIVE TREATMENTS AND IS EXTREMELY DIFFICULT TO TREAT BUT IS CURABLE WITH CHEAP OFF PATIENT ANTIBIOTICS IN THE CORRECT COMBINATION FOR ABOUT 3 YEARS! (a few IDSA lame studies that show that with one antibiotic given for a few months did not improve patient symptoms 5 years post treament is not enough to just say antibiotics doesn't work and therefore don't help sick people) THESE BACTERIA ARE OUTSMARTING ALL OF US, EVEN THE IDSA AND WE ARE NOT GOING TO LET THE MEDICAL COMMUNITY AND THE US GOVERNMENT SWEEP THE OVER 300,000+ CDC ESTIMATED NEW CASES UNDER THE RUG!

Melanie Gaulke Saltzman PLEASE, PLEASE take the time and whatever energy it takes to listen to lyme literate docs, educate yourself and others in your field! Many people with lyme d. are looking for support. WE NEED THE SUPPORT OF THE INFECTIOUS DISEASE SOCIETY OF AMERICA!

Melanie Gaulke Saltzman Thank you very much for your time. Please do something to HELP!

Melanie Gaulke Saltzman Melanie Gaulke Saltzman, Athens, Ohio

Jeannie Bonetpels I have been reading for days now all these comments. What is it going to take for you to understand what all these people are saying and what they are going through? We ARE seriously ill, so are our children and whole families. What will it take for you to HELP US. We are dying a slow miserable death and those of us who aren't here anymore either because Lyme did kill us or we decided we couldn't live like this anymore. Please change everything that you are doing incorrectly and help save our lives. You never know, it could be you with a nasty tick bite or one of your family members.... then what, you are not immune to the ticks poison, just like we weren't. It's time to step into 2012 and DO THE RIGHT THING!!!

Jeannie Bonetpels P.S. Northern California.... New endemic area, just in case you didn't know.

Joni Comstock Please support us by joining this event! http://www.facebook.com/events/310053762368288/

Kelly Demers I searched and searched for my original post.. I guess I hit a nerve with you IDSA... Cant handle the truth?? Removing posts after you asked us what we want for the new year..Is only proving what we all think of you.. It is so disgraceful.. Do you see all these comments IDSA?? We are sick.. Not being treated as human beings. We want what is fair.. To be healthy again... Wouldn't you? We are angry, because you do not listen. What happened to our human rights? Its disgusting that after how long of us yelling for help, you now you ask such a question?? You are playing God with human lives.. recognize the issues.. They are right in your face.. We need help, better treatment, better knowledgeable physicians, and the most important thing... ALLOW the physicians to treat us according to our bodies..Not by what you think is the treatment plan.. Since being sick,with chronic Lyme, my eyes have been open.. I am saddened by my own government, By you, by Pharmaceutical companies.By physicians that follow your ignorant guideline's. By how you black ball Physicians that truly care and are trying to treat us. I have never disliked a organization as much as I do yours. You cannot use one guideline for hundreds of thousand individuals, IF NOT more of us out there! Its right in your face, yet you choose to ignore it.. I leave you with this, We will continue to fight for our rights, we are not going away, there is so many new people getting sick, until one day the world is chronic.. I promise you, You cant keep us all quiet..

Mark Moccio A start would be accurate testing for Lyme and its many co-infections. Actually knowing what you have would be a huge relief for us and a lot easier for our Lyme literate doctor if you can find one. Instead we are blindly ingesting all types of medicines supplements herbals just praying that something might work.

For over 20 years I’ve been lost inside myself. Never allowed to be the person I could have been. Time that I will never get back.

Let’s forget about the past and do something today to prevent this from happening to anyone else.
Please listen to all these people who have suffered physically, mentally and financially as a result of your guidelines. One day it could be you or someone in your family. Maybe then you’ll understand but by then it will be too late as your guidelines will definitely not save you.

Melinda Fulford an honest evaluation of the lyme guidelines you have that keeps our unsurance from paying for treatment for us who have this debilitating disease. It doesn't end after 28 days. If only!

Summer Frundel One of my dearest friends was misdiagnosed for years. After being sick with lyme disease for so long, she finally was diagnosed correctly. TODAY, she is living her life again and actively involved in helping others! Please stop denying that chronic lyme disease exists and spend your efforts on better testing, diagnosis and treatment!

Ravi Kamepalli Lot more involvement in wound care world. IDSA i think has been rather non involved in wound care. Not many infectious diseases doctors are given hands on training in wound care.

Paula Gallo Your strategy to market medications for other illnesses that hide lyme disease is what I might call Psychopathic medicine. Stop lying to people, We don't need a band aid here. we need real solutions.

Lizbeth Binks Carney stop all the CYA'ing and open up to the truth before more people are tragically harmed.

Susan Muik I would like to see the IDSA review and revise your Lyme Disease Guidelines to reflect the ILADS Lyme Disease Guidelines. Please see http://www.ilads.org/lyme_disease/treatment_guidelines.html

Brian Silva @Bill K. ploy or not, you're right :(This is about greed($$$), power, pride, etc... Doing what is right or wrong has no bearing in most corporate or political realms.

Kathleen Angotti ... acknowledgement that what we have is real, better public relations to help others understand what we are dealing with, more scientific research for better treatments and hopefully a cure, easier access to knowledgable doctors and treatment center, having more treatment options be covered by most insurance providers (for the recommended amount of time), a revised set of guidelines to include treatment for chronic lyme and co-infections, educating other specialists on the disease so that they can better treat patients with multiple health issues... These are just a few of the things I would like to see from the IDSA in 2012 - basically, when you sum it up, we just want a little support and some hope that things may change.

Rob Tanner *I would like you to disband since you have your heads buried deep in the sand, are a disgrace to the hippocratic oath, and have lead to the financial ruin of tens of thousands of chronically ill people forced to pay for their own treatment as you give the insurance companies cover to deny treatment. You are a disgrace to medicine*.

April Dawn A way for people with severe disabling chronic lyme disease to get the support they need - medical treatment and otherwise. So many of us are on medicare/disability and that is are only form of income. The truth is that the treatments that help relieve symptoms (that I have found anyway) are NOT covered by insurance - and I am not even sure they are available or how to get them if they were - for example - water therapy facillity that is the right tempature - not filled with chemicals that make me sick - or massage for someone with Lyme/fibromyalgia that is affordable on a weekly basis as it is needed - for that matter - I don't even have a regular primary doctor that "believes" in chronic lyme disease (I don't think she believes in fibromyalgia either) but being on medicare I am lucky to have a doctor at all!!! I need someone to help me find what is available and medically appropriate for someone like me - there may be several services/opportunities but I am too sick to even begin looking if I knew how to look. I need a therapist who specializes in working with somone who has become disabled due to chronic illness - so they can help me manage stress/grief/loss and on and on - I don't know where to look, how to find one if there is one - and insurance - again is a huge barrier. I leave the apartment maybe once a month to go get my labwork done - that is it! I need help getting so many forms of treatment - and I have been struggling with this for YEARS. And there are many many more like me or worse off - we are dying and we need help.

Cindy Reiter Lutkenhaus How about representing the chronic Lyme pts and recognizing that chronic Lyme does exist and allowing MDs to treat this without fear of retaliation from insurance or medical boards?

Petra Bonin Dear members of the Infectious Diseases Society of America

Even if your Lyme-Borreliosis guidelines are not affecting me directly, they affect me indirectly.
I am from Germany and our guidelines are based on the IDSA ones and they bring tremendous suffering in Germany too – in terms of refusal of appropriate therapy by clinicians, to name only one.

In Germany too chronic lyme is negated, downplayed and ignored. I therefore hope that you change your guidelines according to the newest state of science, that you recognize the chronic form of lyme disease and that you discard the 2 week antibiotic therapy as gold standard.

Instead the clinicians training should be strengthened, research must be accelerated and the reams of lyme patients around the world must finally be heard and taken seriously.

Shannon Fiorello I went undiagnosed for 16 years. All three of my kids were born with lyme because I didn't know that I had it when I got pregnant with them. My mom, sister, and husband have lyme as well. My husband is the only one whose immune system is fighting it on it's own. The rest of us need ongoing treatment to stay on top of it. Please open your eyes. There are so many people suffering because of you.

Rob Tanner I would like you to disband since you have your heads buried deep in the sand, are a disgrace to the hippocratic oath, and have lead to the financial ruin of tens of thousands of chronically ill people forced to pay for their own treatment as you give the insurance companies cover to deny treatment. You are a disgrace to medicine.

Judy Titus Drs looking for real answers and not influenced by insurance companies and the likes. Recognition of infectious diseases that exist - are transmitted by various methods - and difficult to test for because they attack the immune system - Babesia and Borrelia to name a few!

Stephanie Vandagriff You have abolutely no reason to delete our posts, besides censoring us. This is the 6th post of mine that you have deleted. They have all been respectful. I only tell my story and respond to your question. You're coming off very shady and hurtful. So I'm going to retail my story and respond to your question yet again. My dad and I both have Lyme Disease. Because of your guidelines, we had gone untreated for 20 years. We now have perminant damage because of it. My childhood and young adult years have been robbed from me because of your guidelines and general attitude towards Lyme Disease. I'm only 30 years old and I am now housebound. Redue the Guidelines on Lyme Disease. Please don't make me rewrite this. I have a right to be heard and have my story told.

Diane J. Marie www.ilads.org

Dolores Claesson
http://sites.google.com/site/floridalyme/memorial-page/vincent-sota

Dolores Claesson Lyme Disease - Jeannette and Al's Story
www.youtube.com
They got Lyme disease in 1994. The wife was bit by a tick and had a bullseye rash. Lyme disease can be sexually transmitted, and that is how the husband got it.

Patricia Marks McDermott As so many others have said, we need honesty from you. Open your minds and see the truth that's out there. If certain members can't divest themselves of conflicts of interest, then it is the duty of IDSA to divest itself of these members. Bring truth and honesty back to the medical community. How many of you are going to wake up one morning and ask yourselves "What have I done?"!!!

Kaethe Mitchell Dear IDSA, thank you for asking for our opinions. I have two children who have neuroborreiliosis, babesiosis, and bartonella. I assume you know the symptoms for these infections and how they can cause a child to lose years of their young lives if left untreated, as is the case with my children. I have a question; perhaps you can help me understand. If a person is bitten by a tick that is infected with any of the known tick-borne pathogens, and the person is bitten in a spot on their body, say the scalp, gluteal fold, axilla, behind the ear, between the toes, or any of the other hidden places on the body (use your imagination) and does not see a bull's eye rash, not because it wasn't there, but simply because it was not readily visible due to its location, and then this person became ill because, let's just say it actually WAS attached for your 36-hour time frame. That can happen, right? Do you agree that this person could go on to develop a tick-borne illness? Did not know why he or she was so ill? Surely there must be a place in your treatment guidelines for this person. Would 2 weeks of doxycycline cure this individual if they came to you, say, 5 years after the tick bite? Where does this person fit in, in your opinion? Do they fall through the cracks and go on to die or commit suicide? What is the future for our person, a life on disability spent in a nursing home, because they do not have Lyme because chronic Lyme does not exist? This wouldn't be post-Lyme syndrome, would it, since they never were treated in the beginning? Please answer this for us. Thank you.

Valerie Mains Wolfer Fifteen doctors misdiagnose a Florida firefighter with ALS. His wife's research ledds them to the correct diagnosis of Lyme Disease.
http://sites.google.com/site/floridalyme/memorial-page/vincent-sota

Amber Chapman Andrianakos IDSA recognizes Lyme only as an acute rather than a chronic disease. I'm living testimony that Lyme is indeed chronic and it is an infectious disease that you either have or you don't. You can't sort of have it. And having it is hell.
My story is this: Two weeks after being bitten while on vacation in Connecticut in July of 2005, I was unable to walk. I told the doctors I felt there was a connection to that bite, but due to lack of information and

misinformation about Lyme, none of them tested me until November of the same year. By that time, the Lyme had moved out of my blood into my tissues and organs. Lyme does NOT like to live in the blood and, unless a special test is used, results will be negative. A false-negative result is exactly what I received.
A few months ago, I went back to the same Infectious Disease doctor I had seen in 2005 for another Lyme test. I tested positive for two bands versus the five bands the IDSA requires for a diagnosis. As with most doctors, he believed it was impossible for me to have chronic Lyme and so he referred me to a neurologist. That neurologist was my 42nd doctor who, again, was unable to help me and was unwilling to treat me for an illness he didn't believe existed.

I know it exists. Every second of every minute of every day. Having Lyme is like having a barb wired electrical fence wrapped deeply around all of my joints. I'm constantly receiving jolts of electricity because my pain is nerve pain. I cry and scream out frequently. I will get electrical "Charley Horses" all over my body, sometimes all at once. I feel like my entire body is on fire and I'm constantly in the bathtub with epsom salts. It is truly a terrifying disease to live through and to live around. And I couldn't live with myself if I didn't try to do something every day to try to right the wrongs that prevent chronic Lyme from being diagnosed and treated and thus stop this hell from happening to others. Finally, after almost seven years of pain and suffering and being in a wheel chair for many of those years, I have been diagnosed with late stage neurological Lyme disease.

I have finally found a Lyme-literate doctor and hope to survive. I'm heart-broken that my disease could have been caught and treated when I first contracted it in 2005 but for the politics that are involved. These years of suffering for me and my family, of seeing 43 different doctors, have been needless and costly. We've spent well over $100k on medical expenses since 2005 and that was before my diagnosis. Fighting Lyme has been a crippling financial burden that we are trying desperately to manage. Now that I have been diagnosed, my insurance will only cover four weeks of antibiotic treatment. My doctors feel it will take eight months to two years if I am to survive Lyme and the co-infectious diseases.

Lyme is costly in many other ways as well. I'm most sad and angry that I am hurting the ones I love the most. Taking care of me is not easy - from bathing to administering my medications to listening to me scream in pain. This is not what my husband and I had planned for our lives. Most importantly, there is the matter of what we want more than anything in this world - to have a baby. It is now not clear if that will be possible. Even if I am able to recover enough to give birth, there is a high probability that the Lyme will be passed to our child. What then? Our child is sick and we're faced with another set of doctors and insurance companies whose hands are tied by the IDSA guidelines? When will this end?

So yes, I have questions: Why is the effectiveness of the test not more transparent to the patient? Moreover, why is the questionable effectiveness of the test not taken into account by the physician? In my opinion, doctors are afraid to go against the guidelines of the Infectious Disease Society of America (IDSA) as that could put them at risk for losing their licenses. How can that be true? Yet I truly have faith that all of us are capable of evolving and that the IDSA decision-makers will hear the call of humanity and rise to the aid of those who need them most - their fellow men and women who need medical care, respect for their suffering, and hope for their futures.

Christina Huhn More integrity with the goal of trying to understand the complexity of lyme disease so that people can get well and live their lives.

Crystal Desert-Diamond Carter The inhumane people behind the evil guidelines have no fear of God

Jean Hemond It took 8 years to obtain a clinical diagnostic by a MD and expert university research microbiologist. The Elisa cameback Negative.

Jean Hemond I did loose 4-1/2 years of sick leave atwork had to retire 3 years early

Jean Hemond Had all the list of symptoms up to lyme rage, spend hundred of thousands dollars in tests scanners, specialists of all disciplines,

Jean Hemond I was tagged as a hypochondriac by local ID, But I told them was before and bitten by ticks that I pulled out, backpacking swamps infected by snakes. How dare your members be so arrogant!

Marcia Stagnaro As a Chronic Lyme Disease patient, I would like to find a primary physician who will accept my diagnosis of Chronic Lyme Disease and who will also accept Medicare as my insurance. Because all the Doctor's I have seen, other than Lyme literate doctors, tell me that according to the CDC there is no such thing as "Chronic" Lyme Disease, I must seek treatment from Lyme literate doctors who Medicare will not certify because Medicare doesn't approve of their practices, which have yet to be approved by CDC. I would like to see IDSA start to pay attention to the thousands of us who have Chronic Lyme Disease and are floundering because the System will not accept our diagnosis. I personally know of sevseral persons who are teetering on the brink of financial ruins, myself soon to be among them, because they have no other choice but to pay fopr medical care which should be provided by medical insurance. The Lyme literate branch of medicine has been trying to reach out and educate the rest of the medical world, but to no avail.

Marcia Stagnaro I would like to see IDSA take a role in closing this gap.

Chris Powell open your minds and get on with treating sick people. we are tired of waiting, tired of suffering and seeing our loved ones suffer. enough BS. Do your jobs, please. change the guidelines so that sick people can get better not spend $ in the medical system being schlepped to doc after doc...unless this is a money making scheme?

Dolores Claesson We have all been quite professional in responding to you and given how you have treated us it is not warranted ! I think we have shown that the brain trust lies with the very ill patients. I am super proud of the responses here !

David Kopelman Lyme disease guidelines rewritten to reflect its true nature/effects and an understanding about proper treatment!!!! Not FALSE understanding!!!!

Laura Klinger Kolaski A cure for lyme

Sat Kartar Kaur what are you doing for the thousands of sufferers of LYME DISEASE?? we are fed up with being ignored and told we dont have this. WHY is there not better accurate testing availible?? the tests are only about 50% accurate and people are mis-diagnosed and/or REFUSED treatment. Wake up America

Stewart Dean An unbiased acceptance of the reality of chronic Lyme disease and an honest effort to help those whose lives are blighted and threatened by it...instead of the current witch-hunting ala Semmelweiss of those who do help us.

Mark Asher It would be really great if anyone at the IDSA actually read any of these comments. But that, as we all know, is not all that likely.

Jonathan Arnow I would like any of the doctors that hold sway over the treatment protocol for this disease to walk a few days in my shoes. Sick with this disease for over 30 years, three kids sick with and possibly my wife also (one kid is OK) and wondering why , when I ask my regular doctor for treatment , he looks the other way.The pediatricians are so under educated. I have been told by a former pediatrician that doctors from our State run hospital have purposefully set out to 'reeducate' the pediatricians about this disease and have initiated a pogrom against any doctor who treats kids aggressively for this disease perhaps knowing that ignoring it will get them more patients. He knows about the disease, God, his kids got it also. I am looking at having to go to a LLDoctor who charges a bundle that I don't have. My cousin was diagnosed with Parkinson's and told to make herself comfortable for the rest of her time. I got her the name of a LLDoctor, who has pulled her back from the brink.How come she's feeling better now? I know of two other fellows who have died from this disease , were sick and family was advised, by reputable doctors , that they had M.S. and A.L.S. Both families were advised to make the best of their situations. I tried to convince them to seek treatment.

Alice Johnson Giunta If you were Real MD's that took an oath to do no harm you would really look at the research and thousands who are still sick...28 days of meds does not work! Over 30 years of debilitating Lyme, now MS (we will never know if one leads to the other) my daughter's life has been devestated, our bank account depleated...and all members affected for life. It's about time you cared about people, not money!

Richard Brooke-Powell I would like you to make it possible for doctors to treat Chronic Lyme suffers properly and with out fear of prosecution. Give them the correct and honest truth about what a huge mistake you have made over the past thirty years and admit it is time for a radical change.

Michael Brochin is a widow maker heart attack associated with lyme disease?

Jackie Zimmerman i would like to see doctors that do not have a conflict of interest write realistic guidlines for chronic lyme.

Stephanie Vandagriff I agree Jackie.

Mark Blood One thing you could do is to update the Lyme Disease information on the IDSA website, which is pathetically out of date. Your "What is Lyme Disease" video features a patient who says she was 100% improved after 3 days of antibiotic treatment, and who ends her comments by saying that she'll tell others that "Oh yeah, it was no big deal". This perfect scenario, where the patient has a visible rash and treatment occurs immediately after infection, should not be depicted as typical. Your "evidence-based" treatment guidelines for "Late" Lyme, which imply that any infection is gone after 28 days of antibiotic treatment, is indefensible because there is no reliable way to determine when the Lyme spirochete is eradicated from the body. I know from personal experience (as a Lyme patient who went undiagnosed for 7 years) that much longer courses of antibiotics are sometimes needed.

Sara Schutz Change your guidelines for Lyme Disease treatment! This disease is a nightmare, and your guidelines are causing many people's lives to be destroyed. Please be honest about this disease. Please, please take these many comments about Lyme Disease seriously. We are suffering!

Pat Bannerman Enough of this political stuff. Get back to doing your job which is looking at the science & up to date research on lyme.. Help all of those that suffer from chronic lyme!

Janet O'Lacey I'd like an explanation as to what happens to spirochetes if they are not completely knocked out by antibiotics. If there's no such thing as chronic Lyme Disease, where do the spirochetes go? Syphilis can remain dormant for decades and then resurface much later. Please explain why the spirochetes that cause Lyme Disease are so different. How do you know for certain that "Post-Lyme Disease Syndrome" isn't really secondary or later stage Lyme Disease?

Michelle Gagnon You erased my comment also. I'm saddened by this cause I am still hoping that you will make it right, allow doctors to treat chronic lyme without fear and adopt the ILADS guidelines that is made by Professionals that actually TREAT Lyme. Look into the science of it. I can see why you are deleting posts because the truth hurts, but this doesn't even begin to touch all the suffering you have caused. YOU CAN make it right!

Gretchen Ahlers Lyme is quite a bit more genetically "smart" than syphilis, by the way...

Valerie Mains Wolfer I would like guidelines to be supported by evidence-based research, not opinions. "More than half of the current recommendations of the Infectious Disease Society of America are supported by expert opinion only, not evidence-based research." http://www.medscape.com/viewarticle/735511

Cheryl Rae Mullenbach-Shoults I have very dear friends with Lyme disease. There ARE treatments for it, both herbal/vitalist as well as traditional/atomist. Both need to be made available to people.

Regarding the following herbal regimen, "chewing" juice means to take a small bit into the mouth at a time and make sure it's mixed well with saliva.

http://www.herballegacy.com/Incurables.html

Suzanne Satya Dev How about a revise of the IDSA guidelines for the treatment of Lyme Disease and it's coinfections? There needs to be an open process that allows all stakeholders a place in the discussion, including doctors known to treat Lyme disease. Who would know better?

Leslie McBain I am from Canada, and your guidelines trickle down to us here as we are following suit. I was misdiagnosed with MS and spent years battling different illnesses of unknown origin. (over 30 years) I was then diagnosed with Lyme and Bartonella and cannot get treatment as we are following your guidelines. I believe doctors should not be penalized anywhere for treating Chronic Lyme and people a with vested interest in Lyme should not be on the board. People are hurting everywhere and need help from you. Can you turn this around and do the right thing and stop the suffering? It could happen to someone close to you. No one is immune. Many years suffering, many years unable to work, many years not being a part of society. A wasted life!

Ann Jacobs Seronello I would like more research on how to treat Lyme Disease and its coinfections. There are some protocols, but more needs to be done. Instead of saying that it may not exist in certain areas, lets admit that it does and treat it appropriately. Maybe then insurance companies will pay for the treatments and those infected can get better soon and get on with their lives instead of fighting to be heard.

Judy Landis Setting Dear IDSA, To have aknowledgement of chronic Lyme and to have revised, realistic treatment guidelines which reflect all known/relevant information about Lyme and associated tick borne diseases would be fantastic. This would eliminate suffering beyond what can be imagined. With long term oral and IV antibiotics, I am no longer a quad, getting my life back, and feeling alive again! I am so thankful for physicians who treat chronic Lyme. If we could all work together to diagnose and treat Lyme, this would truly be wonderful... Most sincerely, Judy Landis Setting

Barb Perry Kinsella *Do not ignore these comments and cries for help. Everyone has a story, and they are almost the same. "Denial" Please stop ignoring that Chronic Lyme Disease exists, people need treatment, people need help. People with Lyme disease are sick and tired of being sick and tired.Very sick people are being ignored by the Medical Systems in Canada, the USA and all over the world. Wake up and listen please !!!!!!!*

Puma Of-Thenorth I can't imagine why the IDSA guidelines for Lyme disease are purposely misleading.

"Five IDSA panelists were found to have conflicts of interest:

1. Dr. Gary Wormser, the panel chair, received funds “from Baxter and Immunetics, and is one of the founders of Diaspex. Wormser also later disclosed he was receiving grants that were related to Lyme disease from Bio-Rad, Biopeptides, Merck and AstraZeneca and that he owned equity in Abbott, and being retained in some medical-malpractice cases involving Lyme disease.”

2. R. J. Dattwyler, is a speaker for Pfizer and a part owner of Biopeptides. Later Dattwyler disclosed he had a financial connection to Baxter and serving as an expert witness in medical malpractice actions.

3. J. J. Halperin, was an expert witness on behalf of Lymerix (GlaxoSmithKline) the failed Lyme vaccine.
4. Allen C. Steere is a consultant for P. J. Krause and Baxter. This is a developer of a diagnostic procedure for a coinfection of Lyme. Later disclosed they found out Steere has a financial connection to GlaxoSmithKline and Viramed.

5. Eugene Shapiro, elsewhere admitted to receiving grants for Lyme vaccines, testifying in Lyme-related medical malpractice actions, and reviewing Lyme disability claims for Metropolitan Life Insurance Company."

Michelle Gagnon Experts on the best way to COVER UP Lyme (far from expert opinion) and get money for research for other diseases that have been used as Lyme cover-ups. There is so much evidence out there that is real, not made up research like IDSA's research. How come the REAL research is ignored? This cover up has been going on for decades. Just read the book CURE UNKNOWN-Inside the Lyme Epidemic by the SCIENCE journalist Pamela Weintraub. The IDSA needs to stop looking through the eyes of ignorance and start following the Hippocratic Oath that swears to practice medicine ethically.

Barb Perry Kinsella Do not ignore these comments and cries for help. Everyone has a story, and they are almost the same. "Denial" Please stop ignoring that Chronic Lyme Disease exists, people need treatment, people need help. People with Lyme disease are sick and tired of being sick and tired.Very sick people are being ignored by the Medical Systems in Canada, the USA and all over the world. Wake up and listen please !!!!!!!

Patsy Swinson I am 60 years old and do not remember a time in my whole life when I did not have symptoms, which I only found out 5 years ago were Lyme and 2 co-infections. Growing up and being sickly as I was, I was on antibiotics many times, sometimes for over a month at a time. Nevertheless, after all those antibiotics, I still had all 3 infections. So obviously a month of antibiotics are not enough in those cases in which a person has had them awhile. I am not alone in this situation. I have lost count of how many fellow sufferers have posted the same problem, only to be ignored or deleted. It is not possible for this many people to imagine that they are too sick to crawl out of bed, sometimes for years. What are you afraid of? Why can't you just do the right thing and swallow your pride? Please.

Mary Corsello-Vilcheck I appreciate this stream ~ Thank you for the question ~ It's evident that many of our lives have changed not only as a result of infection(s), but severe gaps in the system, inadequate lab tests, and medical politics. I ask you to work with the medical community to support labs to perfect, offer, and provide coverage not only for better testing, but also for a different process for the lab 'screening' of Lyme AND associated diseases. It is perplexing and maddening that, in many arenas, a physician will ONLY order a screening 'reflex' test for the Lyme antibody...how can this be? The Western Blot is flawed enough. But at least the doctor would potentially be trying' if he/she ordered it right away. Instead, the doctor looks for the antibody.. if not present, the Western Blot does not even get ordered/tested. OF course, in the case of a patient presenting with a bullseye.. a new bite... antibodies may not even be formed yet. And thus, the patient is sent out with what may be a false negative. How can this unethical, cost-cutting, not smart, awful process be? The WBlot is not good and I do not advocate it; however, if docs are to use it, they should use it responsibly! P.S. I have spoken with numerous nurses, docs, labs, etc. about this..most agree and admit that they have not thought of that. Really?

Cindy Hall Clark In the late 's, my year old daughter was hospitalized with a high fever following a tick bite, she was given IV abx and released with the standard three weeks of Doxy. Six years and over doctors (including ID specialists) later,she was finally diagnosed with Lyme and Bartonella. She was unable to attend school for over years. During that time she was fortunate enough to be treated by two very skilled LLMDs. She took antibiotics for most of that time, including almost two years on IV's. Thanks to the treatment she received (much of which was not covered by insurance thanks to your guidelines) she has recovered to the point of living a fairly normal life (though not totally symptom free). She is one of the lucky ones. We found doctors that do not adhere to the IDSA's treatment guidelines. It is time for the IDSA to wake up and acknowledge that it's guidelines are antiquated, inaccurate and harmful to the lives of patients. After all, as doctors, you took the Hippocratic Oath to "do no harm."

Mary Corsello-Vilcheck Adding ~ Our local Medical Teaching College Department of Infectious Diseases does not test for, treat, or acknowledge Lyme. There are no doctors in my city who are in the know about this. I am a mental health clinician and am dismayed to witness infected clients being diagnosed incorrectly, then medicated accordingly. We must get to the business of doing this right. Thanks.

Larry'n'Rhea Hitsman Stop spreading lies. Change your guidelines on Lyme treatment. Open your minds. Open your hearts. The evidence of Chronic/Late Stage Lyme is overwhelming.

Lynn Olson-Tuma I would like a change in the IDSA's Lyme diagnosis & treatment guidelines. I would also Late-Stage/Chronic Lyme to be recognized a real disease so that those of us suffering with Late-Stage/Chronic Lyme can get the long-term antibiotic treatment that we so desperately need.

None of us who've contracted Lyme Disease asked for it. It is not our fault. We just had the horrible misfortune of being bitten by a tiny little tick that was infested with bacteria. And I think the only thing most of us want is to get well so we can get back to living life and enjoying our short time on this planet.

Nancy Baumgartner Do you serve patients or a system? That is the only question that matters at this point, and I hope it matters to the IDSA.

Jack Vandagriff IDSA, I pity you for the contempt you have earned from good, suffering people. You are pathetic excuses for doctors who have put money and politics above human life. When this goes REALLY public, which I guarantee it will, what will you say to your children when they ask why you let so many suffer and die?

Patsy Swinson I haven't seen any suggestions here about what we want from you that say "Let's just keep the Lyme guidelines we already have", so if you're really serious about your question then many of us sincerely hope that you will take the answers seriously as well. Surely you wouldn't have asked if you didn't want and expect honest answers. A huge majority have answered your question. Now please hear them. Lives literally depend on you.

Annette-Dennis O'Donnell Like most or all of the people on here-2,000, people so far,a tiny fraction of those worldwide who are sick from Chronic Lyme Disease and co-infections-we would like you to change your recommended guidelines for treatment of tick-borne illnesses.Most MD's follow your poorly researched,insufficient precedent and so are left with an often fatal,always debilitating persistent infection.Just like all the people who suffer relapse from syphilis which is a much less virulent strain of spirochete.

Cam Altee Brown I know a cardiologist who was treated at Johns Hopkins for Lyme for one year. So a doctor there obviously doesn't agree with your guidelines either.
Your recent guidelines panel excluded the very physicians who are on the front lines with the sickest patients.

Wormser's conflicts of interest are so monumental he should have never been on the panel. Don't you he is in this fight so deep that he can NEVER tell the truth or he will lose the supposed cred he has. It is like asking a killer to rule on his own appeal.

Luke Miller You could start with an apology to physicians, patients and the general public. We teach our kids the importance of uttering the simple words, "I am sorry." No one is above common decency and respect, please revisit and revise the guidelines, eliminate the lobbyists and educate as many people as possible to help curb this pandemic that will surely leave the decedents of "The Greatest Generation" disabled, helpless and hopeless.

Luke Miller Please eliminate your non-profit status. The conflicts of interest are detestable.

Luke Miller Why is the IDSA not accredited by the Better Business Bureau? Let's start the complaints.

Amy Turner I would like you to do your JOB of PROTECTING the public, not pretending that serious, devastating, epidemic chronic Lyme does not exist! Take your eyes off your bank accounts and look instead at all the needless suffering going on because of your bogus test and your fairy tale "guidelines." So much suffering (and money!) could be avoided if Lyme patients could get proper diagnosis and treatment quickly. Get some REAL doctors and REAL scientists and some HUMANS in IDSA. Start HELPING the American public. Open your eyes, tell the TRUTH, and DO YOUR JOB!!!!!!

Amy Turner I would also like to see all of the ISDA committee members agree to be infected with Lyme and then follow their own guidelines. You would change them quickly.

Houston Lyme Support Group We are a group of hundreds of sufferers in the Houston, Tx. area. We are mostly professional, well educated adults along with a large number of innocent children. We have a huge medical center here with many IDSA member physicians who: 1) refuse to take us as patients due to the Lyme "quagmire"-they know that longer term antibiotics are indicated but don't want to have to deal with the TMB & license concerns or 2) they treat us but won't give more than 4 weeks of antibiotics and when we are not well they say " there is nothing more I can do"-we are pushed out of system-still very ill !! How can a group of physicians turn their backs on patients because a medical guidelines "cookbook" says they are well. Physicians are supposed to treat according to the patients clinical picture and not to a "list."

Many of us are medical professionals who feel betrayed by the conventional system we have been a part of for so many years. We are forced to travel the country to find the few brave Lyme literate (ILADS) doctors there are, resort to doctors who don't really know what they are doing since many can't afford to travel or many are simply losing their jobs/ marriages/ mental health/physical independence/lives due to no options available to them. Is this what a quality physician does to the patients he/she has a moral/ethical/Hippocratic obligation to care for? Our group is growing by leaps and bounds as Lyme Disease is spreading into every neighborhood. This issue is obviously not going way-and yes, we get better when we follow the ILADS protocol !!!!!!!! It is time for the IDSA to get in the game and be a part of the solution and not the problem!

MaryJane Schroeder Plasma...oh yes, people must be careful when accepting blood donations because babesia, Lyme and possibly bartonella can be passed through the blood banks to thousands and thousands of people. I can give a person chronic persistent Lyme! The IDSA should really look into chronic/peristnat Lyme. So far they have blocked any progress of alerting the public to these diseases and have even caused the death of a lot of people by ignoring good old science regarding this!

MaryJane Schroeder Yes, please be part of the solution instead of being the problem! The pain and agony of thousands of Lyme and co-infection patients is on the back of the IDSA! Revise your guidelines and allow people to be treated properly so that adults and worst of all, our poor children do not have to live in pain and lose portions of their life!

Michelle Miller-Anderson I would like you to take Chronic Lyme seriously!

Deborah Perry-Cywink I would like to see changes in how Lyme Desease is treated in Canada. It's a tragedy it is not treated as an infectious desease that can be fatal.

Michelle Murphy IDSA members: Will you even read these?

Mary Ann Griffin Please listen to people who are sick with an infectious disease and try to figure it out. Stop spending time & money writing guidelines so you can avoid getting close to the sick people (you might catch it!)

Chris Lesinger Emsley I would like to see them acknowledge Chronic Lyme Disease and revise treatment guidelines to reflect science and input from the Institute of Medicine Worshop. I have a dear friend who has suffered from this terrible disease for years. The difficulties in getting treatment have only made a terrible affliction that much more challenging on her and her family.

Bill Klavonski I've seen some comments on Lyme boards that this is going viral. If it doesn't go further than this it won't. Please consider getting the attention of as many news sources as you can. I've sent the link and info to the Drudgereport. Let's keep this moving. This has to get outside of FB and into main stream media. What can you do to help?

Jeanine Cox I have a 12 year old boy who has lost a year of his life (so far) fighting this debilitating disease after multiple misdiagnosis and a negative Elisa. I also have a 14 year old girl who would have had to accept chronic headaches, and more subtle symptoms if it wasn't for her brother's diagnosis which led to her CDC positive test result.

Jeanine Cox How long are you going to let people suffer like this?

Sandy Sidah *You need to review the Lyme guidelines. You know it and everyone else does if they have been touched by Lyme. My life has been devastated because the physicians who I trusted can't or won't diagnose Lyme or even explore whether it could be. Now after all these years of seizures and other neurological and physical symptoms that are definitely Lyme related, I finally get a diagnosis. Is it in time to save me? I wonder. This could have been prevented. Do physicians care? Does IDSA care for the suffering Lyme patients have?*

Tammi Dawson We/ Lyme patients have raised so many concerns that the IDSA guidelines do not address the needs of individuals with Lyme. What I would like to know is, why is the IDSA ignoring us and not taking the proper procedures, making it harder for necessary for changes to take place? What happen to our rights and choice of healthcare? This is not science, it is fraud! Bottom line- please hear our voices. ... We need your help and recognition! Enough is Enough! We have a right to be healthy and happy individuals!

Kathy Rottier You guys are so WAY behind the times with Lyme Disease. I had a CDC positive result from Igenex with almost ALL bands in the 3's and 4's, and your IDSA doc told me that I didn't have Lyme disease, that I was depressed. Do you know what that does to the pysche of a very physically sick person!!!!!

Penny Lillis Real help from doctors across the US and for the IDSA to acknowledge the coinfections of Lyme and proper treatment for Lyme patients. We are suffering out here without proper medical help! Please help!

Fredericks Research on where the Bb organism hides in chronic Lyme disease and the symptoms it causes.

Brett Emsley Dear IDSA, To have acknowledgement of chronic Lyme and to have revised, realistic treatment guidelines which reflect all known/relevant information about Lyme and associated tick borne diseases would be fantastic. This would eliminate suffering beyond what can be imagined.

Mariangela Comelato Remetz please, please, please, revisit the Lyme Disease. guidelines! My daughter missed all 4 years of HS due to this and some other co-infections. She will probably never be back to 100%. Look in to your hearts and remember the oath you took when you became medical doctors."First, do no harm"

Cathy Sing So sad for us that we get looked at cross-eyed by Doctors when we mention Lyme, I have been to so many specialists, the last one was the ID Doctor in Lewes DE that actually said "there is no such thing as chronic Lyme" I was very confused and feeling maybe I am turning into a crazy hypochondriac. After considering that my symptoms are real and have been for many years, I hoped that his children never get this dibilitating disease to have his eyes opened to the suffering it causes.

Mariangela Comelato Remetz Too many of us have been harmed for too long. Please help put an end to it! YOU CAN DO IT! You have a responsibility to all your patients and collegues. We are not going away!

Denise Weaver Good Morning...will you be sharing the outcome of this data collected? Thank you.

Susan Swinson Williams My January 5th 1:32pm post was deleted, and it wasn't even offensive or rude, lol. Did I hit a nerve, IDSA?? All I said was basically Stop making Lyme Disease about politics and start supporting the patients and their doctors... allow the suffering patients and their doctors decide on their treatment options, rather than bureaucrats who don't have the patient's best interests at heart. Are you listening yet? Or will you continue to ignore the almost 2,000 people who have posted here and the thousands more around the world who are suffering because of your actions? Deleting our comments won't make us stop or go away, but merely proves to show what cowards you are.

Angela L Westbrook I've endured 10 long years of SUFFERING DUE TO YOUR 'GUIDELINES!' I've been misdiagnosed for years due to doctors/clinics that are ignorant to the true facts about Lyme/co-tick infections because of your incorrect guidelines. I've been misdiagnosed for years due to inadequate testing because of your guidelines! I've been turned away, REFUSED to be seen/treated, by many (including our states University Hospital!) after finally finding a diagnosis of Lyme because they are fearful (of lawsuits from insurance co's) or unable (their hands are tied because of the system they work in) to treat due to your 'guidelines.' Even though I have good health insurance, I'm left with huge bills that my insurance refuses now to pay because of your guidelines. I'm now left unable to work, and unable to be the wife, mother, friend & woman the Lord created me to be because of your guidelines! It saddens me to think how different my life would be had I been properly diagnosed & thus properly (NOT 3 weeks!) treated right away. People are suffering, dying, going broke, watching their lives wasted, left crippled and/or bedridden because of your guidelines! Wake up! Open your eyes! Put evidence before money & politics! Help us! CHANGE YOUR GUIDELINES REGARDING LYME & TICK BORNE INFECTIONS!

Helen Samson Mullen Please could you acknowledge chronic Lyme and provide revised, realistic treatment guidelines which reflect all known/relevant information about Lyme and associated tick borne diseases.

Peter Kemp Dear IDSA. Please look at my experiment for culturing spirochetes from people with long-term illness:

http://www.counsellingme.com/microscopy/bskculture.html
Would IDSA members or groups please
1. reproduce the experiment and
2. investigate what these microscopic spiral agents are,
3. find out why they take months to grow and
4. explain why antibiotic treatment (as per IDSA guidelines) does not eradicate them?

Many Thanks for your consideration

Jeff Christnagel Why do so many GULF WAR era veterans with illnesses defined by Gulf War Illness also suffer with Lyme?

Leslie McBain Our blood is on you hands if you don't make this right!

Lynn Crosby You need to listen to ILADS and patients with chronic Lyme. They do

Lynn Crosby know what they are talking about.

Suzanne Pelletier Homeopathic treatments for LYME publicized in addition to antibiotics (Japaneese Knotweed, Lyme nosodes, Vit. C power & sea salt, Herbalist Lyme Tincture, etc.) and the need to supplement D and B12.

Paula Gallo I'd like to know what President Bush was given to cure his Lyme disease.

Susan Figurski Please save the walking dead

Carlos Diaz a cure for chronic Lyme disease

Gretchen Ahlers Peter Kemp, Thank you for embodying passion for truth! You redefine for us what science and medicine is!!!

Sandy Sidah You need to review the Lyme guidelines. You know it and everyone else does if they have been touched by Lyme. My life has been devastated because the physicians who I trusted can't or won't diagnose Lyme or even explore whether it could be. Now after all these years of seizures and other neurological and physical symptoms that are definitely Lyme related, I finally get a diagnosis. Is it in time to save me? I wonder. This could have been prevented. Do physicians care? Does IDSA care for the suffering Lyme patients have?

Rob Tanner How about you have your Lyme disease guidelines committee travel around the country visiting various LLMD practices and exposing themselves to actual patients actually being crushed by this actual disease. I also suggest you conduct a large scale study using the new (and very expensive) culture test on a sample of the patients you will meet at these practices who could not even see the inside of a mainstream hospital ID Dept due to the consequences of your so called guidelines.

Next, sack the guidelines committee (since you will now have evidence of their negligence) and replace them with a mix of genuine researchers and LLMDs.

Finally change your name to IDSA (under new management now treating diseases actually caught in North America rather than just foreign ones).

I know that's not as snappy but the original was kind of innately ironic.

Rob Tanner When I caught schistosomiasis (swam in Nile, bit dumb) I saw about 8 doctors before I found one who diagnosed me. He was an ID doctor who was super psyched to see schisto as I guess he didn't see much of it in Chicago.

When I caught Lyme disease (walking in a forest in Michigan, not so dumb) it again took about 8 doctors to get diagnosed. The difference was this time my local ID Dept (UW Madison hospital) wouldn't even see me. My excellent MD spent 40 minutes on the phone with the ID doctor who made the decision not to honor her referral. At the end of the conversation she asked him "are any of your colleagues more sympathetic?" to which he replied "no".

FYI, the Lyme symptoms are an order of magnitude more disabling than the schistosomiasis symptoms were, yet you were excited to treat that. I guess I should apologies that my boring home grown disease is so uninteresting to you?

Denise Obrien 10 years because of your guidelines. Massachusetts does have chronic Lyme. I am living proof. I was once a successful business woman now I am a disabled single mother trying to raise a daughter with down syndrome. In the past 10 years my symptoms have progressively gotten worse. Lyme has taken over my body. It has infected all of my joints, my nerves, has affected my heart, my kidneys and even my brain. I am one of the lucky ones who now have drs that do believe that I have chronic Lyme. It is because of your guidelines I cannot get proper treatment. Financially it is impossible for me to afford to treat myself. The cost ranges between $1200 - $4000/ month for medication, supplements, labs, and dr follow ups. Now with proper treatment I can be possibly cured but most certainly improve a lot more. As a single mother if is disabled daughter who CAN NOT be cured I am all she has. I beg you to re visit your guidelines. My daughter needs me and Lyme is killing me. Do not ignore us. Our lives are in your hands and families are suffering. Thank you for taking the time to read this. Please take the time to make the changes to fix this.

Gretchen Alhers "I wouldn’t expect any problem at all for the president,” said Gary Wormser, chief of Infectious Diseases at New York Medical College and an expert on Lyme disease. “He won’t be impacted by this infection in the future.” www.washingtonpost.com/wpdyn/content/article/2007/08/08/AR2007080802268.html

Gretchen Ahlers Regardless of political orientation, could it be that poor advising regarding Lyme disease is affecting American diplomacy? http://www.pensitoreview.com/2007/08/08/bushs-doctors-kept-Lyme-disease-secret-for-a-year-is-the-condition-why-his-mind-is-degenerating/

Jeannie Bonetpels Thank you Peter Kemp. Fascinating. IDSA needs to check out that link! Seriously!!!

Dedee Simms Millage Colorado does have chronic Lyme. Are you afraid of what will happen to the insurance companies if you change the guidelines and start to treat Chronic Lyme? I get that you could be afraid of another economic crisis, but believe me, all the money that, in my case, has been spent on MRI's, Cat scans, ER visits, ultrasounds, mind numbing medications, dozens of different specialists, etc... is WAY more than it would have cost to put me on long term antibiotics. Just sayin'

Sam Malone Gretchen, in that article(2007) they mention STARI which they claim isn't Lyme disease, although it looks just like it, but it doesn't show up in serological tests. It has since been found that there's a previously undiscovered borrelia species Borrelia lonestari, which is the infecting agent behind STARI and is indeed Lyme disease. How many more species are there that haven't been discovered yet and don't show up in tests?! http://www.ncbi.nlm.nih.gov/pmc/articles/PMC356874/

Borelioza We want the truth about Lyme disease!!! http://www.miklossy.ch/

Eric Anderson Even the founding members of the IDSA are coming around. http://www.Lymediseaseresource.com/wordpress/chronic-Lyme-disease-validated-by-founding-member-of-idsa/

Sara Connor http://www.youtube.com/watch?v=t247gCqBrTU&sns=fb

Jody Zuk Julian The Lyme Epidemic--as is more than apparent from these responses-is wrecking people's lives. If it's about the money, consider that you'll save money if everyone followed the latest Lyme disease protocols and threw out the old 'gone in 21 days with doxy' in the garbage where it belongs. Give us back our lives.

Sara Connor http://www.youtube.com/watch?v=LK2a3PrAXeY&feature=player_profilepage

Jody Zuk Julian And will you get rid of the patent on Lyme Disease?? That would be helpful. It's not a corporation. OCCUPY LYME!

John Coughlin http://johnnylight.proboards.com/index.cgi?board=medicalinfo&action=display&thread=251

Welcome - Small ticks still make you sick johnnylight.proboards.com

Peggy Boyce Furey revise your guidelines and stopopposing legislation designed to help educate the public and help patients get treatment for Lyme disease.

Keri Ellington Aragon I don't see the share button for this post anymore. Anyone else notice that?

Peggy Boyce Furey Stop persecuting doctors who treat patients outside your guidelines or disagree with your guidelines

Laurie Damsell Fahey I would be happy to show the IDSA documented pictures of active ongoing infections in my body.

Elise Brady Stop being controlled by the big corporations, go back to science and do what your organization was designed to do! Lyme disease is killing people and babies and your organization has a responsibility to report all of the evidence!

Brian Crosby Dear IDSA, please acknowledge chronic Lyme and revise your guidelines so they are realistic, balanced, and reflect the ILADS guidelines. To not do so, would cause even more suffering and pain then you already have.

Mary Bush Keri Ellington Aragon -- the share button is there, take another look. best wishes.

Puma Of-Thenorth What I would like to see from the IDSA this year regarding Lyme disease guidelines ~ Truth honesty & integrity would be refreshing & a nice surprise.

Irene Stewart A fair and unbiased look at ALL the research on Lyme and its co-infections

Karen Schlangen Steele Get rid of the corporate interests and the conflicts of interest. When those are gone, the truth of science will scream out loud! So many people are sick and you are spreading inaccurate information and "guiding" doctors to not treat Lyme aggressively. It really gets "under my skin!"

Cathi Gallucci Ruiz I just want to get back to the life I had and loved before. Why is it so hard to just to a have a normal day?

Michael Feinberg I would like to see the IDSA take a realistic look at Lyme Disease diagnosis and treatment, avoiding any outside influences, inviting those deemed "Lyme Literate" to the discussion table and revamping the inadequate guidelines that currently exist.

Susan Shields What would we like to see??? Well, first we'd our "infectious Disease Society" to recognize and admit that Lyme disease, along with the other vector co-infections, is a grave and dibilitating disease. One that has the ability to take lives, literally! Instead of feeling like they must be part of a "secret" society, allow Lyme patients the privilege of being able to discuss this disease openly with their doctors instead of being looked at like they are crazy!! It's bad enough to be so severely ill, but it's a whole other event in life to be made to feel the disease isn't real and the symptoms are all in their heads!!

Wendy Vogt *Unchecked epidemic that has disabled previously employed people... when it starts affecting our economy, it gets the attention of legislature and they are asking why it has gotten to this point. All fingers will be pointed at you. I wouldn't want to be in your shoes this year. Good luck with that.*

Kelly Mairson *Your response- "Providing guidance for good patient care has always been and will continue to be a cornerstone of our society's mission"*

Think you should think about changing your "mission."

I seriously don't think 2,000 patients would be complaining if that was the case.

George R Stallone The current IDSA Guidelines for the Diagnosis and Treatment of Lyme and its associated Coinfections can best be described as a Crime Against Humanity. Attempting to use ones credentials as a physician to define away a disease causing this much morbidity and mortality for personal financial gain is purely criminal. Receiving the backing of a prestigious professional collaboration such as the IDSA for this crime undermines the reputation of the entire medical community. Such individuals as Drs Wormser, Shapiro, Dattwyler,Steere and the rest of the Lyme panel should be censured by the IDSA in order to protect the professional reputations of all it's other members as they are sure to be the subjects of countless individual and class action liability law suites over the coming years. I find it personally insulting to think that these men put on white lab coats and used their credentials as physicians to lie about a disease in a way that directly contributes to the morbidity and mortality of thousands of people annually. To think that the IDSA allows them to use its name and reputation to give validity to this criminal act of deliberate medical malpractice leaves me wondering what the future of the medical community may be. When I look at the fact that the CDC itself admits that it's survalence criteria only documents 10% of the actual Lyme cases annually and that these current IDSA guidelines on Lyme claim that the CDC survalence criteria leads to excessively high false positive diagnoses it becomes clear that the morbidity and mortality directly resulting from these guidlelines is truly massive. When one looks at the spread of this disease AS IT IS DOCUMENTED and then allows for the rate of undocumented cases, it becomes clear that Lyme is rapidly becoming an undiagnosed, untreated epidemic. I can only hope and pray that investigations into this panel does not show that the attempt to define away Lyme disease came from a desire on the part of the medical community to continue to profit from the unending symptomatic treatment of countless "syndromes" that have no cure while recognizing that the appropriate diagnosis and treatment of Lyme disease will lead to a relative rapid and inexpensive eradication of these "syndromes."

Susan Shields Another comment I must make is that I think I can actually understand how all the AIDS patients felt back in the late 70's and early 80's. Look how long it took doctors to accept that AIDS was a force to be dealt with! One question I'd like to ask our "infectious Disease Society", it Lyme disease can be "cured in 7 - 10 days with one round of antibiotics, then why won't Insurance Companies allow people infected to get life insurance policies??? I know this to be a fact because my niece who has been battling this wicked disease for almost 2 years tried to have her life insurance policy amended, and her insurance company would not grant any increase because she quote "had an incurable diease"?

Some thing is terribly wrong to say the least!! Doctors must become trained in how to treat this plague and must all finally agree that long term antibiotic treatment is a MUST is there is any hope of living a normal life. Oh, and how about funding research to find a definitive test that will diagnosis Lyme and they how about a cure???? What do we want from you people?? That is almost an insulting question, even though I'm very glad you finally asked it!!!

Jean Hemond Lyme Disease denial by IDSA is about intermingled power, politics and money ;Not science medicine and research as it is pretended. Otherwise IDSA actions would be accordingly directed to benefit the patients by orienting research spreading the factual information as experienced by hundred of thousand patients. And finally you would help official medicine to revisit millions of erroneous medical diagnostics for desperate terminally neurological sick peoples caused by IDSA official Lyme Disease denial and ignorance.

Cam Altee Brown Asked in the 80s why the gay community found it necessary to be so loud and obnoxious concerning AIDS treatment, a gay friend said, "Because our lives depend on it and we don't have time to play nice."

Cam Altee Brown I agree with what George R. Stallone said above. The IDSA is doing its own reputation a disfavor by letting Wormser, et al speak for them when it comes to Lyme Disease. Physicians that continue to see Lyme patients walk through their doors are tuning into the disconnect between the guidelines and what is necessary to treat. And what does the establishment do but hunt them down, threaten to pull their licenses.

Barbara Campbell Your response to these concerns and posted comments is a blatant lie. The current IDSA guidelines are not reflecting the most recent studies and unfortunately keeping those who need treatment in the dark. Their physicians are afraid of treating chronic patients properly for fear of getting on the "witch hunt" list. Insurance companies have to man up and begin covering the long-term treatment that is necessary to treat chronically ill Lyme patients.

Julie Ridl The poor GPs in my hometown in Michigan are struggling with more and more patients who are wildly sick after not being diagnosed with Lyme in time, for lack of obvious rashes, lack of positive ELISA tests, etc. When these late-disseminated cases are finally diagnosed, through positive Western Blot, the local IDSA docs have no interest in their cases. Local ER docs have less understanding than the GPs do, blatantly insisting that Lyme is rare in our area (despite recent biological studies), and having an ancient picture of the disease manifestations in their minds. Isn't the IDSA supposed to be a beacon of wisdom, education and support for persons with infectious diseases? Particularly for emerging and spreading diseases Lyme. With the Times reporting indicators that this will be the worst year in record for Lyme disease, it would be wise to get your act together NOW, before Spring brings more suffering and more broken families to this country.

Response from the Infectious Diseases Society of America IDSA appreciates all of the passionate responses. Although we aren’t able to respond personally to each comment, we want to assure you that we take note of the input. IDSA’s member-physicians are concerned about the full range of infectious diseases, including HIV/AIDS, drug-resistant infections, influenza, tuberculosis and many others, in addition to Lyme disease. Providing guidance for excellent patient care is our goal, and relying on science and medical evidence is the best and safest way to achieve that.

Joël Ruhlmann Please recruit some LLMDs for the next guidelines !

Kelly Mairson Your response-
"Providing guidance for good patient care has always been and will continue to be a cornerstone of our society's mission"

Think you should think about changing your "mission"

I seriously don't think 2,000 patients would be complaining if that was the case.

Julie Ridl And so, we need much more science and medical research for tick-borne diseases.

Michelle Perry What kind of response was that???

Joël Ruhlmann Take note of the input... Great. And then, will you change anything?

Wendy Vogt Unchecked epidemic that has disabled previously employed people... when it starts affecting our economy, it gets the attention of legislature and they are asking why it has gotten to this point. All fingers will be pointed at you. I wouldn't want to be in your shoes this year. Good luck with that.

Virginia Wuellner Ward I would like to see recognition of chronic Lyme Disease by IDSA. Many of us have CLD, but cannot get our ID drs. to recognize this, thus meaning our insurance will not pay for treatment. PLEASE take seriously our symptoms and recognize that they are chronic Lyme.

Marsha Marcinko REAL research and real evidence of the truth about Lyme disease reflected in your current guidelines.....acknowledge the truth. And by the way, it's okay to admit it when your wrong...I am living proof that you can have Lyme disease and never see a tick, or present a rash (and yes I tested positive for it). I am living proof that it took more than 4-8 weeks of antibiotics to get rid of it...it took 11 months, and a whole lot of pain, patience, and perseverence...after being denied a diagnosis or testing for 5+ years due to your misguided guidelines...Do what's right.

Response from Infectious Diseases Society of America *IDSA appreciates all of the passionate responses. Although we aren't able to respond personally to each comment, we want to assure you that we take note of the input. IDSA's member-physicians are concerned about the full range of infectious diseases, including HIV/AIDS, drug-resistant infections, influenza, tuberculosis and many others, in addition to Lyme disease. Providing guidance for excellent patient care is our goal, and relying on science and medical evidence is the best and safest way to achieve that.*

Ashley Ordecki That is all we want! For your guidelines to relying on good science and medical evidence instead of money. If it was then you wouldn't have almost 2,000 responses of almost all lyme concerns.

Christian Hornung @IDSA: Thanks for your answer. But I'm very sorry to say, that the IDSA guideline isn´t the best advice for patients with Lyme disease. This guideline is for many people the beginning of their chronic Lyme disease. The studies, which are building the basics for the guideline, aren´t up to date. These studies are confuted. The guideline of ILADS are the best offer for patients with Lyme disease!!! Wake up!! Adapt your guideline - be human - help the people! Your point of view is unjustifiable!

Kimberley Foster healthy people don't bring in the bucks so there is no research that will ever make this so.

Lin Huhn Check out the sick people and the doctors who treat them. I am stunned by your answer. Ignorant doesn't begin to cover you or the MDs who misdiagnosed and mistreated me for 20 years.

Ginny Coon Walcott Acceptance of the truth and acknowledgement of Chronic Neurological Lyme Disease!! WE WON'T BE SILENCED! Millions of victims have been forced to leave the workforce due to its debilitating symptoms and destruction it causes when left untreated or under-treated. CDC guidelines MUST be rewritten...yesterday.

Lisa Shogry Savage The ISDA's response is expected, but still greatly disappointing. Ironically, I must fly to the DC area to reeceive treatment for my Lyme disease, since it "doesn't exist in South Carolina." Did the IDSA place the GPS on ticks so they know not to cross into other states? Seriously, if this issue wasn't so painful financially, physically, and emotionally, it would be laughable. I am thankful that I have the resources to complete my treatment. It is a TRAVESTY!

Gretchen Granner Maronde An honest review of the Lyme Disease Guidelines looking at the science presented at the IOM (Institute of Medicine Committee) workshop and acknowledging that all is not known about this emerging complex disease with its many co infections.

Ginny Coon Walcott Yes, it is a travesty, Lisa. I was denied IV antibiotics by insurance company. My stomach, gallbladder, bladder, kidneys, and liver cannot handle the oral antibiotics, which I took for 1 year. My appendix was so infected with Lyme bacteria that they were surprised I survived. And so I try to get through each day with as little pain as possible, praying for an answer to this nightmare. God be with all of us.

Monica Humbles More work in the connection between IC and Lyme disease and it's connections

Michelle L. Saxon Dear sirs, frankly, it's too late for what i'd like to see from the IDSA in this coming year because what I'd like to see is my mother again. She passed away in August from chronic undetected for at least 20 years, untreated in time Lyme Disease with secondary Scleroderma. You all need to listen. You all need to get a grip. Open your eyes, help these people crying out to you - again, it's too late for my 67 year young mother, but it is not too late for some of these people who are so very ill. You'll be held accountable in front of your maker when your time is up.

Michelle Greene "IDSA's member-physicians are concerned about the full range of infectious diseases, including HIV/AIDS, drug-resistant infections, influenza, tuberculosis and many others, in addition to Lyme disease." What a hoot this statement is by IDSA. I don't know about the rest of you but how much public information on Lyme disease is available vs the information (and medical resources) available for HIV/AIDS, influenza (wow, what a debilitating disease), tuberculosis, etc. In addition, when was the last time a physician had to fear losing his/her medical license for treating a patient with an infectious disease, other than Lyme?

Stephanie Vandagriff At least IDSA finally responded, but that was the crappiest response I've ever seen. Just because you release a statement claiming things, doesn't make it true. Here is a full response they made on us, really disheartening.

Stephanie Vandagriff
www.Lymedisease.org/news/touchedbyLyme/idsaresponse.html

Kenneth Poindexter IDSA,.I don't know if you've noticed that there is barely a handful of responses here regarding anything other than chronic Lyme disease. It is clear that there is a huge disconnect or denial on the IDSAs part regarding Lyme vs other diseases. There is a huge outcry for help. Why would the IDSA even ask for what we want and then turn around and respond in such a "let's make like Lyme isn't as important as every other disease' response. Put the resources into fixing the wrongs surrounding the Lyme treatment guidelines. Quit pretending like it doesn't exist or isn't as huge of an issue as it is. That's all we ask.

Christine Keller I am disgusted and furious with the IDSA response - or lack thereof - the usual treatment. I n the IDSA to Hitler - you ARE RESPONSIBLE FOR THE DEATHS AND DESTRUCTION OF THOUSANDS OF LIVES. Plain and simple. It is clear you do no and will not conduct yourselves ethically. I personally will see to it that on a national level you ALL will ANSWER for the lives you have and continue to take. This is not the end, but the beginning of your end. Lyme patients, I need each of you to write your local CDC, AG, Senators, Reps, Legislators, and media collectively. This is officially a movement ned to nationwide tobacco class action suits, and "occupy America". I can't do this without each of you emailing your stories and documentation to the above mentioned contacts. Now, today, OUR VOICES AND SUPRESSED SCIENTIFIC EVIDENCE WILL BE HEARD!

Tina Cyr Livingston I would like the IDSA to hear our voices. I have been told many times that I do not have Lyme disease because of negative ELISA tests. I have had bulls eye rashes since 2006. No one knows what they are, why they are there and they do not go away. I have been told that I am tired because I have four children; I am depressed, etc., etc. By the way, I was given 3 weeks doxy each time a rash showed up, but I guess that really doesn't work. Then when I had a positive WB last summer I was told by ID doctor that it was a false positive, the rash was an allergy. After he did allergy testing (and it turned up negative). I was told "you have a mysterious illness. I don't know what it is. You should go to dermatology and get some steroids-that ought of take care of it" (already had a biopsy done in -nothing) I thought ID doctors were suppose to investigate these mysterious illnesses. Especially in the state of MA where we are suppose to be doing lots of research. And in his arrogance, he totally didn't hear my arthritic, neurological and pain symptoms. I must have been making them up. I gave up on ID and headed for an LLMD. Low and behold she was able to diagnose over the phone. The rash was from Bartonella. After more testing - it was confirmed Bartonella and Lyme. After 3 weeks of antibiotics - Low and behold I started getting pigment in my skin where I had vitiligo. Now unfortunately, I first came down with vitiligo during my first pregnancy. Guess what? I have two kids with autism and one with ADHD. Coincidence???? THINK NOT!

My entire family is infected and nobody ever listened. The pediatricians won't even return my phone calls. I thank GOD for my LLMD every day. If it wasn't for her I am sure that I would be dead by now and my young children would have been next. Shame on you for the secrets. This is costing us lots of money out of our pockets, because the insurance companies won't pay for IV treatment and the probiotics we have to take with orals are costing families a fortune! You need to educate your colleagues. Massachusetts is infested with ticks. At least 5 of my neighbors have been ill and lots of my friends. Please treat tick borne disease until they are dead, not a mediocre 3 weeks. Everyone is an individual and each responds differently. Your guidelines are outdated and are not allowing many caring doctors to treat the way they should.

Paul Lattuca Dear ISDA, Please make 2012 the year we solve the puzzle of Lyme Disease and the co-infections that go along with it. We need better testing, more effective treatments, and informed doctors who are willing and capable of dealing with tick born diseases. A few suggestions might include funding research into better methods of culturing Lyme and Bartonella so that we can directly identify what is making patients sick or forming a national Lyme Disease Forum where researchers, doctors, and patients can share information openly. Best of luck to you in 2012... A lot of people are counting on the ISDA to lead the way in the battle against Lyme!

Donna Zukaitis Falcone IDSA... pathetic.

Deb Wilson Please, let go of your egos, open your hearts & listen to the patients who have followed ILAD's guidelines & regained their health. Lyme is a complicated illness. After a tick bite I followed your tx guidelines only to become very ill. When testing positive months later I began to investigate all the different points of view. WOW! What is all this about? The patients are clearly the ones who are suffering as a result of these conflicting views. I'm not a fan of long term antibiotics, but after speaking with over a dozen people who live in my community - that was the recommended treatment that seemed to get results. Do you have anyone on the board who has chronic Lyme?

Scott Reed *Under your Lyme Disease Guidelines many patients have been harassed, belittled, falsely accused of psychosomatic disorders and broadly misdiagnosed in general.*

Under your 2006 Lyme Disease Guidelines many patients have been denied coverage of medically necessary treatment from their insurance companies.

Under your 2006 Lyme Disease Guidelines many patients continue to get sicker.

Under your 2006 Lyme Disease Guidelines many patients have lost their livelihood, houses, families and suffered great economic tragedies.

Under your 2006 Lyme Disease Guidelines many patients have died.

Until you experience this disease I don't think you can appreciate the complexity & how disabling it can be. Please open your minds & more importantly open your hearts!

Kaethe Mitchell My children's poor pediatrician followed the IDSA's guidelines and ordered the faulty ELISA for my kids when they presented with Lyme symptoms. The test was negative, so they went on to become more and more debilitated as time went on. It's not the pediatrician's fault the guidelines are outdated, if they even WERE in date at any time in the past. Now she sees my kids, whom she has cared for since they were babies, suffering with late-stage Lyme and co-infections. I wish I could post here what "H-E-Double Toothpicks" my kids have gone through these last two days in terms of suffering, but I will protect their privacy and dignity. Suffice it to say, IDSA, no one should suffer like they have, especially as a direct result of negligence by a medical society that should be protecting its citizens from infectious diseases, but is instead preventing them from getting a diagnosis and effective treatment.

Bambi Albert So your saying 1,975 CHRONICALLY ILL People with Lyme disease is NOT enough medical evidence?????

Beth Pattz We are not going away!!!! Ever:)

Scott Reed IDSA, thank you for your response and recognizing the passion behind the posts as this condition has traumatically touched the lives of so many. I really do believe that the majority of your member-physicians do care about the quality of health care they provide. All infectious diseases are equally important to the patients whose lives are touched by them.

Providing guidance for excellent health care should be priority number one with a large influential organization like the IDSA. Many doctors around the globe have taken your guidance to heart and have used that guidance to treat their patients, and with the case of Lyme disease, that's a big problem.
Under your Lyme Disease Guidelines many patients have been harassed, belittled, falsely accused of psychosomatic disorders and broadly misdiagnosed in general.

Under your 2006 Lyme Disease Guidelines many patients have been denied coverage of medically necessary treatment from their insurance companies.
Under your 2006 Lyme Disease Guidelines many patients continue to get sicker.
Under your 2006 Lyme Disease Guidelines many patients have lost their livelihood, houses, families and suffered great economic tragedies.
Under your 2006 Lyme Disease Guidelines many patients have died.

This is NOT excellent patient care, you have momentously failed your goal when it comes to Chronic Lyme Disease. Please, again I beg both, you as an organization, and you as individual member- physicians, to revoke the poor guidance you have provided with your current Lyme Disease Guidelines.

I believe the IDSA can make a difference in providing top notch care, they have the resources that are needed. Science and medical evidence support the ILADS guidelines. Science and medical evidence, including the thousands of posts you have received have shown your guidelines are wrong. Science and medical research have shown it's time for a change in policy. Do the right thing and show the medical community that sometimes as fallible humans we don't always get it right.
YOU can achieve your goals, and WE can help!

Respectfully,
Scott Reed
Father of 19 year old daughter bedridden with Chronic Lyme Disease.

Joanna Clifford Magoon After 5 years of treatment for Lyme with a very brave, very wise Doctor, so far so good. make it easier for doctors to think out of the box and treat according to their well-honed instincts and experience - not by some watered down, ineffective guidelines. I weep for those thousands of Lyme sufferers who are inadequately treated because those who make the treatment rules do so without insight, openness and courage.

Carla Brown It took THREE YEARS for me to beat Lyme Disease. I hope you look at the actual medical evidence and rewrite your guidelines instead of using biased evidence that fits your agenda.

Hollis McGuire I was treated in 2003 for Lyme disease but did not get better. It took me 7 years to find an LLMD while I grew more ill each year. Two years in treatment and I am now well again. The traditional level of treatment works for some, maybe for most, but it is not adequate for all, and those who remain ill should not be ridiculed or turned away.

Bambi Albert so why is it of all the things you have posted here, Lyme Disease got the most response????

Kenneth Poindexter IDSA is clearly censoring comments. I have seen 10 comments deleted in the last 20 minutes.

Melissa Griegel Your guidelines are completely inaccurate and causing pain, misery, financial loss, degradation of health, stress, and illness to millions of people.

Roz Wesolaski Milano IDSA.......please take responsibility for the reality of Chronic Lyme, 2000 comments cannot be wrong......whether or not you look at this realistically, eventually the truth will come out, just AIDS.

Melissa Griegel What would I like to see?
- research about chronic Lyme
- accurate guidelines
- unbiased doctors writing your guidelines
- a Lyme vaccine
- more education, obliging more accurate information, for doctors
- an accurate educational campaign for everyone in the US
- removal of the ridiculous notion that 3 weeks of doxy us a cure-all
- better Lyme testing
- more info, research and testing on all of the co-infections
- a CURE!
- an apology to every Lyme patient who was mistreated, not diagnosed, or humiliated by doctors who are

members of the IDSA and follow your inaccurate guidelines like a bible.

Melissa Griegel If anyone of your members actually got Lyme disease, they would no longer dismiss the notion of Chronic Lyme and
would understand how devastating a disease this is, and realize that 3 weeks of doxy is not enough.

Dave Bassett I would like the IDSA to look at the real facts of Lyme disease, including the research done in Europe, rather than its own "cooked facts" promulgated by the same gang of ten yalies, "peer reviewed" by the same gang of ten yalies, and published in the same five journals. It's not working for you anymore. Medical care providers all over the country, and I'm not talking about Lyme specialists just oridnary primary care providers, can see your society's guidelines are totally divorced from clinical reality. You are and deserve to be a laughingstock.

Jill Justiss IDSA, you said: "IDSA is an active, member-driven society and as such, this question was intended for the 9,000 or so IDSA member physicians, researchers and healthcare providers who are concerned about the full range of infectious diseases including drug-resistant infections, influenza, hepatitis, HIV/AIDS, tuberculosis and other life-threatening diseases."

If you do not want an opinion from the patients who are directly affected by your guidelines then I suggest you delete your facebook page and find another way to communicate with your member physicians, researchers and healthcare providers. I find your dismissal of 2,000 comments from chronically ill patients and ignorance to the reality of this disease disgusting.

Heather Lynn Please refrain from asking vague questions if you are going to ignore the genuine responses trying to advise you of where your society fails. Your society has failed the public. That's all the response you deserve.

Hazel Raby I would like the society to open their eyes to what is going on around them concerning Lyme Disease. Deleting comments is in the same vein as ignoring the voices of so many sick people. Your society will suffer due to this callousness and blatant ignorance. By making this question public you have shown your hand in how you treat others.

Kelly Patton Nanney Same old response. Year after Year while this mess with TB [tick-borne] Illness continues to ruin the lives of so many. The parents of these sick children are on the move. My kids aren't going to go through all this suffering for nothing. The truth will win.

Sharon Hawkes IDSA, in your reponse you said, "Providing guidance for excellent patient care is our goal, and relying on science and medical evidence is the best and safest way to achieve that." Evidence-based medicine was defined by Dr. David Sackett as consisting of research evidence + clinical experience + patient preference. If the evidence is lacking (the IOM conference said it is, and the IDSA guidelines review committee said it is), then clinical experience and patient preference should carry more weight. Is the IDSA really practicing evidence-based medicine, or isn't it?

Melissa Griegel Why are you opposed to finding out the truth regarding diagnosis and treatment of Lyme?

Joy JustJoy I'd like to see ALL of the Lyme crooks who are responsible for all of this human suffering BEHIND BARS!!! That's what I would like to see in 2012!

Lisa Hilton IN your response you stated that you would have more to gain by prescribing long term abx. Why would that be if none of your panelists have any conflicts or interest by having ties to insurance, pharmaceutical companies, stock in vaccines?? Just curious.

Paula Gallo There is one who is the head of infectious disease medicine at Norwalk hospital. Are you kicking back vacations to these docs? how much are you paying them to lie for you?

Holly DuVal I would like to see more doctors get on board with recognizing the signs and symptoms of Lyme disease, especially chronic Lyme. I have been suffering for several years not being able to figure out what is wrong with me. I now have been being treated by a Lyme doctor who is wonderful for the past year. I am still very sick, have been in bed for over a year now, if This was caught earlier then maybe I wouldn't be so sick now. I am having iv treatments now, I hope this is the key. Thank you

Melissa Griegel What would I like?
- three years of my life back
- three years of my kids' lives back with a healthy mom

- all the money I spent getting myself better because if I had been diagnosed and treated more accurately, I would have gotten better much faster and my insurance would have paid for it

Sylvia Reisman Glover Dear IDSA Board Members, as your organization bases the Lyme disease treatment guidelines on scientific facts, you have just recruited 2,000 + patients, which you could use in a "Clinical Study". This is what you need, in order to have evidence to make the necessary improvements/changes to the Lyme treatment guidelines. I have a feeling that most people posting here would gladly submit their labs, patient history and outcomes as a result of being treated with long term antibiotics vs short term treatment. The resources (patient group) is here at your fingertips. You only need the staff to contact the patients and collect the data/facts to complete your revised study.

Sara Schultz I would like the IDSA to provide the public with documented proof that the pharmaceutical industry does not profit from the diagnosis of "Post Lyme Syndrome," or any of the other chronic illnesses late-stage, disseminated Lyme disease can mimic, including Multiple Sclerosis, Fibromyalgia, chronic fatigue syndrome, Parkinson's, Lou Gehrig's, Altzheimer's, arthritis, anxiety, depression.

Tessa Mccall I would like to know what IDSA has done with the information provided during the IOM conference in October 2011. This conference was requested by Congress. Why would Congress be involved if they thought there was unanswered questions. I believe there was acknowledgement that tick borne illnesses are serious and have become a major problem in our society. How many more people need to effected by this horrible disease before the IDSA will admit that new studies need to be done with an open mind. We are not the only country being effected by tick borne disease. From what I have read some countries have already acknowledged chronic Lyme disease and are working from this standpoint. Hopefully, IDSA will acknowledge this truth before another country outlines what IDSA has known. ITS REAL- ITS HERE - AND ITS NOT GOING AWAY. Come down off the pedestal and converse with the people fighting the enemy (the bacteria and parasites).

Jaisibel Sullivan Please point us to clinical trials showing that 28 days of antibiotics helps those who are sick from Lyme.

Mindy Schwartz Diepenbrock Please make 2012 the year we solve the puzzle of Lyme Disease. I can't bear to watch my 7 year old struggle with chronic Lyme any longer. The six weeks of antibiotics she was given barely scratched the surface of her symptoms. I am praying for IDSA to really listen because I do believe all medical doctors take an oath...an oath to do no harm. IDSA guidelines are harming many many chronic Lyme sufferers.

Carl Tuttle The online petition against the IDSA member's Lyme disease study has gathered 211 signatures from across the US, Canada, Germany, UK, Ireland, Belgium, France, and the Netherlands. Please take a moment to read why people are signing this petition.

There are now seven states which have passed legislation to protect clinicians who treat late stage Lyme with long term antibiotics (CT, RI, MA, MN, NY, NH, and TX) and there are support groups in nearly every state with nineteen in Pennsylvania alone.
If the IDSA and CDC got it right with their "one size fits all" treatment approach for all stages of Lyme disease and faulty two tier test algorithm why then do we have this much legislation involving Lyme disease?

Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-Lyme-disease

Carl Tuttle
Hudson, NH
Website:
http://home.comcast.net/~runagain/site/?%2Fhome%2F

Shawn Denman You to hear them, you to look at them and not just what the drug and insurance company's tell you to see and think.

Ariel Marquet A lot of people on here posted peer-reviewed medical evidence of persistent Lyme disease. How is that not evidence based medicine?

Hillary Laughlin Lyme Disease get the Changes that are way Past due !!

Also IDSA STOP Blocking Lyme patients .. Just for saying the Truth of what Lyme Disease Is !!!

Dr's need get facts on this and know Lyme is EveryWhere !!!!!

IDSA Come on and do What is Right !!

Diane J. Marie www.ilads.org

Carl Tuttle I would like to bring to your attention the following statement from testimony by Dr Paul Mead, Medical Epidemiologist with the Division of Vector-Borne Infectious Diseases, National Center for Infectious Diseases at the Centers for Disease Control and Prevention.

Testimony:
http://www.hhs.gov/asl/testify/t040129.html

“No surveillance case definition is 100% accurate. There will always be some patients with Lyme disease whose illness does not meet the national surveillance case definition. For this reason, CDC has stated repeatedly that the surveillance case definition is not a substitute for sound clinical judgment. Given other compelling evidence, a physician may choose to treat a patient for Lyme disease when their condition does not meet the case definition.”

Federal Public Law 107-166 passed by the Senate and House and signed by President Bush on January 10, 2002. Wording on that bill states that the CDC's case surveillance definition is "misused as a standard of care for healthcare reimbursement, product (test) development, medical licensing hearings, and other legal cases." It also instructs the CDC to correct this misuse.

The CDC has done a disgraceful job of correcting the misuse of their case surveillance definition.
For example, you will see the CDC’s case definition referenced in Aetna’s Clinical Policy Bulletin below but nothing stating that it is for “surveillance” purposes only:
http://www.aetna.com/cpb/medical/data/200_299/0215.html

Carl Tuttle
Hudson, NH
Website:
http://home.comcast.net/~runagain/site/?%2Fhome%2F

Diane J. Marie IDSA posted above: "Providing guidance for excellent patient care is our goal, and relying on science and medical evidence is the best and safest way to achieve that." Reponse: There is not one word of truth in that.

Kenneth Poindexter Hey IDSA- I did a random sampling of 1,861 of the comments that have been posted on your question, here are some stats:
Total Comments Parsed: 1861
Lyme 1341
HIV 55
DrugResistent 0
Tuberculosis 4

Distinct Posters 1188

Kenneth Poindexter ^^^ This is how you make use of data ^^^

Kenneth Poindexter Seems theres a clear interest in having the IDSA review its Lyme Guidelines

Kenneth Poindexter Oh, more information. If the 55 comments that pertained to HIV, 45 of those comments also mentioned Lyme disease. Seems even people that care concerned about HIV are also concerned about your problems with the Lyme guidelines

Laurie Geromel Robell It is clear that there is a huge disconnect or denial on the IDSAs part regarding chronic Lyme disease vs other diseases. There is a huge outcry for help. Put the resources into fixing the wrongs surrounding the Lyme treatment guidelines. Quit pretending it doesn't exist or isn't as huge of an issue as it is. That's all we ask. There are 10s or 100's of thousands of people that are affected by Chronic Lyme Disease, and many are going undiagnosed, because the IDSA definition of Lyme is so restrictive, and the medical and insurance systems are following those very restrictive guidelines. Why is the 2nd level Lyme Disease Western Blot test according to IGeneX standards not run on more people? The ELISA test only screens 50% of Lyme-infected people. Why does insurance only cover 30 days of IV antibiotics for Lyme Disease, when those that are going for 1-2 years are getting much better? Why isn't more research being done? Why isn't other testing and other Lyme research experts being concerned in the data that the IDSA is collecting? This is a travesty, and those of us in the middle of it, go through huge heartache and expenses because of such restrictive guidelines, that are avoiding early diagnosis and the treatment required. If you want to help, bring in people from the other side, instead of simply denying it doesn't exist.

Kenneth Poindexter Please excuse the typos in my comments, I am suffering from Lyme disease too.

Kenneth Poindexter Of all the comments, 428 indicated that someone was suffering. Of those 428, 379 are suffering from Lyme, 14 are suffering from HIV, 0 are suffering from Tuberculosis. This is a clear indication of where your agency needs to focus its efforts in 2012. I'd be happy to share my research with you. Please contact me via private message for more information on how you can get this data too.

Diane J. Marie A post of mine was just deleted in the last five . It carried only the ILADS logo and their URL.

Kenneth Poindexter Oh wait, one more stat for ya. Of the 1341 comments about Lyme disease. 525 of those are pertaining to Chronic Lyme. Seems that Chronic Lyme does exist.

Sara Schultz Burying your response in a 2,000+ post is not an acceptable response, IDSA.

Diane J. Marie www.ilads.org

Sara Schultz Apparently, of all the infectious diseases the IDSA provides guidance for, Lyme patients appear to be the least pleased with your guidance....

Alison Nash Needelman *There is so much more known know now about Lyme and its co-infections. You favor old and biased research. Please review the Lyme Disease Guidelines presented at the IOM (Institute of Medicine Committee) workshop and acknowledge that all is not known about this disease and its many co infections.*

Stephanie Vandagriff Sorry Diane. They only want to see and hear certain things. Anything outside the bubble is a threat, and by me saying this, my comment is probably going to be deleted.

Alison Nash Needelman There is so much more known know now about Lyme and its co-infections. You favor old and biased research. Please review the Lyme Disease Guidelines presented at the IOM (Institute of Medicine Committee) workshop and acknowledge that all is not known about this disease and its many co infections.

Deb Compton-Venezia I am just gonna be direct and say it; they simply just don't care if we flood them with questions. They just don't care about the loss we have suffered with, if they did would we even be here still demanding some common decency? We protest, we write letters, we tell our stories, but still it lies on deaf ears. There comes a point when we must just realize that "we the people truly do not matter to them". It is easy for them to hide in their fancy homes and drive their fancy cars ...They aren't worried about these guidelines because they can BUY their HealthCare! Sadly, Money is Power! I am sure if any one of us were rich enough we would find a doctor out there willing to treat us medically and speak to us with respect. That response IDSA gave? I mean C'mon it is so talking in circles ...it is like when ya had a really tough test in school and you talked your way into a better grade than you deserved? lol I think most of you will know what I mean; I know for sure the IDSA does cause they use this type of manipulation everyday in their carefully, clever response which basically offers us Nothing. I

DSA Panel, if what you do helps patients and gives them the "best possible healthcare" than why are we all here saying what we are saying? It surely isn't for wealth; we have nothing to gain, actuality we have everything to lose. I don't want any special treatment; I just want to be treated with dignity when I tell a doctor my medical history and symptoms. I just want to be treated with the respect I deserve, instead of being belittled. If you don't have enough "evidence" to back up Lyme Disease then DEMAND more research and believe me ...we know there isn't enough research ...the last 30 years the information on Lyme (tick-borne diseases) hasn't changed that much, that truly is pathetic. Maybe we don't know all the answers, maybe we all might be right in some areas and wrong in others... the point is we need to come together for the betterment of the public, for people’s well-being. These guidelines should be re-written because they give doctors and insurance companies and excuse to neglect. YOU know it does! Sighs, I don't want to bicker with the IDSA, I just feel you NEED to back your WORDS up with ACTIONS.

....Show the people we are important, show us that you work for US and not the pharma and insurance companies. SHOW us differently and I promise you then we will believe. Until then ...I feel we are all wasting our time, because NO ONE is listening ...they just simply do not care! Much Love ev1 and blessings ..and yes even to you IDSA, because I pray you are never poor, I pray you are never on the other end of the suffering you have contributed too ...I pray because it just isn't in my nature to wish harm onto others just because they brought harm onto me. I choose at this moment to Not let your neglect and ignorance consume me anymore. I might have to suffer with pain til the day I die, I will not get medical care because of you, we will do without much, but our hearts will be full because we chose not to become just like You, IDSA.

Nicole Morter Recognize chronic Lyme disease for what it is, and start treating people instead of giving up on them!

Darlene Franklin Kohler For the IDSA to really look at all the useful Lyme Disease data and research which has been gathered by many physicians but unfortunately has been previously ignored by the IDSA.

Robin Burke Ferryman "An honest review of the Lyme Disease Guidelines looking at the science presented at the IOM (Institute of Medicine Committee) workshop and acknowledging that all is not known about this emerging complex disease with its many co infections."

Sarah Jean I would like the IDSA to stop picking for themselves what they deem as science and what medical evidence they will acknowledge.
How about this for scientific and medical evidence:
I was bitten by several nymph sized ticks while hiking in an area northwest of Lake Tahoe (in California, not Nevada). I didn't realize they were ticks at first, and thought it was just specks of dirt covering my arm. Approximately four weeks later I was hit with the craziest assortment of signs and symptoms. I didn't know which doctor I should go to first. A gynecologist? A rheumatologist? A cardiologist? A psychiatrist? It took me going to four different doctors (I am one of the lucky ones who only had to see four doctors before getting help, rather than the dozens or hundreds that others see) before finally being tested for Lyme and co-infections. My lab results came back as CDC positive for Lyme disease. I also had a clinical diagnosis of Lyme, Bartonella, and Babesia. I was prescribed a round of Doxycycline for 4 weeks, but became symptomatic again immediately after stopping the Doxy. I then re-started antibiotic treatment, this time under the care of a Lyme Literate Medical Doctor, who rotated and alternated different antibiotics, anti-malarials, supplements, and treatments infrared sauna and massage. After two and a half years of this intensive regimen I was finally symptom free. I went from being house-bound/bed-bound, unable to function, and in absolute misery; to being able to work and exercise again, and symptom free.

Since finishing treatment and being asymptomatic for 3+ years, I have had both regular physicians and infectious disease doctors try to tell me that I never had Lyme, and that Lyme doesn't exist in California. They told me this without looking at my records and without listening to my story. They heard the key words of "California" "Lyme" and "long term antibiotic treatment" and immediately blocked any further conversation.
Ridiculous.

Beth Stormont Really, IDSA? That's your response?!? REALLY?!? Why did you even bother to ask us? Thanks for nothing.

Cam Altee Brown Remember the physicians who were mocked for believing hand washing could stop the spreading of germs.

Remember the physician mocked for believing ulcers were caused by bacteria.

Professional physician groups have held steadfast to their out-of-date beliefs at what cost?

People's lives. People's bodies. People's finances.

Lives have been decimated because Wormser eta al are too proud and stubborn to say they were wrong. They can fix this while they are alive or they can go to their graves clinging to their stubborn beliefs, and the Lyme Community will ensure their legacies reflect the abysmal so-called evidence-based medicine they practiced that harmed so many.

Cam Altee Brown How much does Dr. Wormser get paid to testify in court on behalf of insurance companies by saying he is right and everybody else is wrong?

Patrick Christell I will add my voice to the considerable chorus of people sounding off about this. To me, it is simple. If the board members are getting money from insurance companies, their guidelines will reflect the whims of those who bribed them. Forget science, forget the human toll. Greed is the sickness that has swept the world, and it's especially sad when it spills over into areas that affect life and death. To the IDSA board members: The word is out about you and your shameful "guidelines." Once the walls to real treatment have been torn down, and your ignominy is exposed to the world, you will join the ranks of the forgotten many who tried to stand in the way of truth and progress. This day cannot come a moment too soon. I'll say it again. You will all be forgotten.

Robin Krop To learn from ILADS how to test for Lyme and co-infections and treat. Not to use the ELISA test as a screening test - it's useless. To use IGeneX testing, but know it will only catch people 60-70% of the time who have the infections, so to treat clinically by history and symptoms. To understand longterm treatment is needed for chronic Lyme. To have insurance companies cover treatment. To learn from patients.

MaryJane Schroeder How other one? Yes, please be part of the solution instead of being the problem! The pain and agony of thousands of Lyme and co-infection patients is on the back of the IDSA! Revise your guidelines and allow people to be treated properly so that adults and worst of all, our poor children do not have to live in pain and lose portions of their life!

MaryJane Schroeder Will this message stay?

Martha Champion I have been sick for 25 years. Finally diagnosed with Lyme after many many doctors, many tests. I now have Chronic Lyme and 25 lost years of my life. I found a LLMD and am paying out of pocket for my treatment. Please acknowledge this disease and help people. We will all help you if you need histories.

Lisa Collette O'Neil the truth about trying to get a Lyme disease diagnosis ... and then the truth about trying to get treatment once you do get a diagnosis...which can take years...thousands of dollars and the loss of ones health, family and friends in the process. it is criminal what Lyme patients have to go through just to get well

Marcus Davidsson IDSA why do you claim to represent science when you in fact ignore science?

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Sue Larkin Duckworth "Providing guidance for excellent patient care is our goal, & relying on science & medical evidence is the best way to achieve that." That is a really fine mission statement, if the anecdotal and scientific evidence showed that to be true about the IDSA. It is a sadly disconnected self-image you have of yourselves. Two separate, published research studies, by your own IDSA members, dispute your reliance on science and medical evidence in providing guidance for excellent patient care. Yes, that would be the best way to achieve that goal, but you are not doing that. The truth is, according to the studies, only 1 in 7 IDSA treatment guideline recommendations use high quality data from clinical trials. More than HALF of the recommendations rely solely on "expert opinion" or "anecdotal evidence." And 37% of the IDSA's strongest recommendations are based on the weakest evidence, which would be opinion, again, yet self-proclaimed to be "A" level evidence. And no 'expert' on the committee takes exception to this during the meetings? This data was based on reviewing 4200 IDSA guideline recommendations issued between 1994 - 2010. One researcher admits," we are all operating on a lot of bias...we all struggle with this, even as experts..." The IDSA responded in defense, not with thoughtfulness or objective scientific introspection-- "the public can have absolute confidence in these guidelines, & they are the best that science and medicine have to offer." After those statistics?!

Please let some faction in the IDSA step outside of the politics and power and rescue this organization. The opportunities to corrupt guidelines are great. There have been many conflicts between professionals within disease states, bias due to research studies, data entered into guidelines based on personal interests, or preservation of professional reputations when guidelines are short on true medical evidence and long on 'expert opinion and anecdotal evidence.' That is when clinician judgment and experience, and personal research should be accepted AND encouraged by the IDSA.

If only you presented your guidelines with this objective, unthreatened approach; non prosecutorial towards clinicians who treat based on guidelines and symptoms of individual patients. Being a scientist includes emptying out expectations, observing, having a critical eye and an open mind to wherever the evidence leads, which it seems has been replaced with just being right, and that you know better. What chance is there, for these mere patients, families, and friends (some are doctors, too) who have earnestly written to you on this site asking you to listen to them with fresh ears? What will pierce this callous, glazed, stare down your IDSA noses attitude towards this bothersome crowd, who are messing up your pages with different facts, personal testimonials, and plenty of reason to consider that for a start, the thousands of symptomatic people, untreated due to false negative ELISA results, end up with chronic Lyme? When does the excellent patient care begin here, I challenge you?

Karin La Mothe Recognizing chronic Lyme Disease's existence. Once established, ensuring proper training of ID doctors to utilize appropriate effective lab testing for Lyme diagnosis. So much trauma and suffering are avoidable if doctors used effective testing methods.

Sara Connor Please answer me this IDSA
How much money has been made off the faulty testing for Lyme Disease?
How many Americans are suffering today because of these tests?
If you boarded an airplane and there was a 60% chance that the plane was going to crash would you get on that plane?
We would be very lucky if 40% of the Lyme disease cases are picked up with the current testing from the dearborn conference 1994.
Check it out for yourselves!
these papers are the FACTS!!!!!!!!!!!!!
http://www.actionLyme.org/DEARBORN_WHO_SAID_WHAT.htm

Sara Connor The IDSA has it's hands on the tail of a tiger with Lyme disease.
They better think about how they handle this MAJOR problem .
SILENCE AND CHANGEING THE SUBJECT WILL NOT WORK!
OUR NUMBERS ARE GROWING AND WE ARE NOW IN THE HALLS OF OUR GOVERNMENT FROM THE STATE LEVEL TO THE FEDERAL LEVEL GIVING THEM THE FACTS ABOUT WHAT HAS GONE ON WITH THIS DISEASE!

More and more elected officials find that tick borne illnesses have arived at their door steps and they too have joined us in this battle.
KEEP UP THE FIGHT!!!!!!

Małgorzata Szkutnik Not only Americans, Sara Connor. We suffer because of IDSA all around the world. I'm in central Europe, I'm 30, my Lyme is 29 and I truly hate IDSA.

Bill Klavonski People... This isn't going to go anywhere until it gets into the hands of the major on-line news outlets. The IDSA can delete this thread anytime they want and all these posts will have been in vain. Do you really think the IDSA is listening? CNN, MSNBC, Drudgeport, you name it. Get this out there. This hasn't gone viral yet! It's still just a facebook page. Help me spread the word.

Jennifer Merritt Heffler I would like to see more educated health care providers, more funding for proper testing, and less hassle for all affected with Lyme Disease. It is about time that Lyme had more awareness (from all parties) so that we can properly diagnose, treat and prevent it.

Leslie Laughter Ellmore I understand you (IDSA) supporting your guidelines and research that you quote to back them up...But, what ever happened to encouraging doctors to be inquisitive, as opposed to dismissive? If you don't think that lyme disease can be chronic, then please try to find answers, and not imply (or state) that symptoms are all in the patients' heads.

Jeri Hemerlein Stop deleting the posts you don't like for a start ..that would help

Marilyn Emerson Sims A new, updated and comprehensive look at Lyme disease, how it is diagnosed, how it can be better treated/managed, and investigate diligently chonic lyme disease. Thanks.

> **Nancy McCaskey** *I have medical insurance, yet have spent $50,000 out of pocket last year alone fighting Lyme disease, and my daughter is dying. My insurance company will not cover most of the treatment because of IDSA guidelines. These guidelines need to change. This illness is devastating families.*

Kenneth Poindexter Bill Klavonski - All of these comments are being backed up. IDSA can delete this thread at any time, but they cant delete the comments. I will personally print out this entire thread and deliver it to every newspaper in the country if I need to. We will not be silenced anymore

Mary Ladd How about this.. If you're not going to change your ways, at least do this-

Mary Ladd throw a line in your guidelines that says "if you are unsure how to treat Lyme disease, then direct the patient to The Turn The Corner Foundation so they can help them find a Lyme literate MD." You see, anyone that WE know already knows about you. I am worried about the future patients that don't understand this mess. Which by the way, is a big mess. Then you don't have to deal, and the patient can get the care he/she deserves RIGT AWAY instead of your Dr's thinking they can play God. Then slapping a diagnosis of let's say for ha ha's Fibromyalgia on them. Which leads me to my next question...what exactly is that? And what causes it? Just saying.

Kim DeSantis Goodwin How do you sleep.knowing your destroying millions of lives?

Bill Klavonski Kenneth Poindexter - Awesome. Thank you so much. That's what we need.

Laurie Damsell Fahey Just give up this disease to a different area please.. your science makes no sense at all because we are all still sick.. give us a break and just admit that you are clueless what a mess!

Nicole Leyane There's a chance that my comment was deleted as well. LYME DISEASE! Re-evaluate the guidelines! Thank you to all of the posters for the support!

Laurie Damsell Fahey PS Using your own research to back up your bogus guidelines doesn't count. Use Lyme doctors how can you use IDSA doctors who openly admit they don't treat Lyme Disease and turn you away? I have been in this situation! Have you???
January 10 at 10:58am · Like · 11

Nicole Leyane I'm sure multiple people have said this already, but the sad thing about this is that we need

notoriety to FORCE change to happen... and soooo many people have lyme and don't even know it.
January 10 at 10:59am · Like · 10

Carl Tuttle Response from U.S. Senator Kelley Ayotte in reference to the online petition against the wasteful Lyme disease study "SUBJECTIVE SYMPTOMS AFTER TREATMENT OF LYME DISEASE
Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-lyme-disease

Carl Tuttle
Hudson, NH
Website:
http://home.comcast.net/~runagain/site/?%2Fhome%2F

January 5, 2012
Dear Mr. Tuttle:
Thank you for your comments regarding research programs funded through the Centers for Disease Control and Prevention (CDC). I appreciate hearing from you.

Like you, I believe that CDC's federal research dollars should be wisely allocated and used for meritorious health-related endeavors. CDC programs should be held to the highest standards and must be closely scrutinized.

As our country faces a serious fiscal crisis, we have the difficult task of reining in a massive national debt, while at the same time encouraging economic growth and providing adequate funding for important national priorities, such as disease and injury research. We must get serious about cutting all spending that is redundant, inefficient, or wasteful.

I deeply appreciate your concerns that taxpayer dollars used to fund the CDC be used responsibly to contribute toward beneficial research programs. I will certainly keep your comments in mind as I address the grave fiscal challenges we face as a nation.

Again, thank you for taking the time to contact me. As your Senator, it is important for me to hear from those I represent regarding the current issues affecting New Hampshire and our country. Please do not hesitate to be in touch again if I can be of any further assistance.
Sincerely,

Kelly A. Ayotte
U. S. Senator

KAA/bf

Valerie Mains Wolfer
http://lookingatlyme.blogspot.com/

Sara Connor WHO SAID WHAT AT DEARBORN.
THE LYME TESTING THAT WE HAVE NOW SHOULD HAVE NEVER BEEN PASSED!
WHO SAID WHAT AT DEARBORN.
1) Gary Wormser at New York Medical College- Steere's method detected 9/59 cases
2) Igenex- Steere's IgG detected 8% of the cases
3) Imugen – Steere's method detected 14% of the cases
4) Wisconsin—Steere's method was 15% accurate
5) UCONN- Larry Zemel was referring to Lyme as comparable to juvenile rheumatoid arthritis. Recommended adding band 50 for children's blots.
6) Roche—28% were positive for 5 of 10 Steere IgG bands.
7) Wadsworth – had some different scoring system. Did not report on accuracy of Steere
8) Ontario Ministry of Health
9) Lutheran Hospital— 22 % were accurate by Steere's IgG
10) MarDx Labs – recommended adding bands 31 and 34, but were given CDC positive arthritis positive blood to falsely qualify their test strips. Theirs were used in both vaccine trials.
11) CDC Atlanta – talked about mice, not humans. The mouse criteria was 2 out of three from OspC, 16 kD, 17.9 kD, for the mice.

Susi Kaster Glaeser Why can't you make a comment ISDA??? Now you don't have a word to say??? Not one opinion or thought??? Not one response to the over 2000 infectious disease sufferers.... cowards!

Meo Doyne You say "Providing guidance for excellent patient care is our goal, and relying on science and medical evidence is the best and safest way to achieve that." AND I say, what about taking into consideration the clinical evidence -- some of which you have before you in response to this post. Medicine and science have NOT fully studied such a complex organism as Lyme Disease or the co-infections. You need to base treatment guidance on the success of treatment for the patience, which has been sorely lacking under the current protocols...

Jean Hemond What about Babesia from Lyme co-infections in the blood-supply being the major factor in many growing neurological syndromes.

Shannon Evans Roberts I wonder what would happen if the majority of the powers that be in your organization became infected/suffered with Lyme disease/Chronic Lyme disease....would you take it seriously then???? Would you continue to put the issue on the back burner while people continue to suffer??? Just a thought......

Mary DeLisser No, they'd treat it as it should be.

Martina Bussmann Faurschou Change the Lyme disease guidelines!!

Stephanie Vandagriff For those of you who don't know, the IDSA did respond to our post. It was a crap response, but still a response. www.lymedisease.org/news/touchedbylyme/idsaresponse.html

Bonnie OKeefe First, I don't consider the IDSA "MY" society.....! I would like to see your guidelines on Lyme reviewed, (with ALL new sources of scientific information and research available), updated and brought into the 21st century. I would like to see you have compassion for the suffering of thousands of people in this country and worldwide and be truthful and honest concerning the existence of and treatment for chronic Lyme. I would like to see how YOU deal with your family and loved ones who, Lord forbid, contract Lyme. I would like to see the IDSA return to the protection of the citizens of the United States as their #1 priority. I would like to see swift and honest education of all medical personnel concerning the truth and treatment of Lyme disease. All this is wishful thinking...hopefully in my grandchildren's lifetime?

Douglas Maass I would like to see a more rational, reasoned approach to chronic Lyme Disease from IDSA, one that recognizes its existence and actually tries to offer understanding and relief to thousands of victims currently being ignored or being told it's all in their heads.

Ingrid Boutilier McAdam I recently read a comment on here that referred/dubbed the IDSA as the "White Coat Tailed Mafia". Which is absolutely untrue and unworthy! You folks and your organization should not be regarded in this class. The Mafia is quicker and cleaner, they wouldn't leave you to suffer for decades...nor are they, as far as I know , into murdering innocent children. No......you guys are in a class of your own.

Mary DeLisser Well said, Ingrid. Tuskegee Phase II??

Michelle Newell Actually, the fact that the CDC uses the IDSA's Lyme Disease guidelines makes them just as guilty of neglect as the IDSA. The IDSA was charged with giving 'best practices based on sound scientific data without bias' guidelines' to the CDC and instead the IDSA has falsely provided inaccurate and fraudulent information to the CDC regarding treatment of Tick borne diseases. If anything, the CDC should be notified of the IDSA's inability to provide accurate data and guidelines that have put hundreds of thousands of people at risk of illness and death and immediately call an investigation of these facts.

Wendy Vogt At 12:41 yesterday, IDSA added a response to this thread - scroll back if you want to waste your time reading it. It was patronizing and showed no interest whatsoever in this disease. None. Spend your energy promoting those groups that ARE on top of the latest medical info - these people aren't. Give ILADS the attention... these people don't deserve it.

Mary DeLisser I respectfully disagree, I think we are getting to them

Nancy McCaskey I have medical insurance, yet have spent $50,000 out of pocket last year alone fighting Lyme disease, and my daughter is dying. My insurance company will not cover most of the treatment because of IDSA guidelines. These guidelines need to change. This illness is devastating families.

Carol Hanna Wilson I'd like for this disease to be brought into the forefront so that doctors are looking for that instead of sending us all over creation to be told we have lupus, chronic fatigue, delusions, hypochondria, etc. If regular testing for this disease was done, so many cases would be caught and treated and heartache and money would be saved. My son and I are still in treatment going on 1 1/2 years. My family will be tested every four to six months for the rest of our lives. I've paid so much out of pocket for treatment that prevention and early detection for the rest of my family is well worth the money. For goodness sake, the flu shot is all over the place and I wouldn't put it in my body, yet millions are spent brainwashing people that it's necessary. The waste of money on things we don't need is OK, yet education on tick borne illnesses is non-existant.

Melissa Ann "the public can have absolute confidence in these guidelines, & they are the best that science and medicine have to offer."

Actually, they are not the best that science and medicine has to offer(WE HAVE ILADS - Thank goodness!). There is not much science behind them at all....just the so call "expert" opinions of corrupt IDSA panel members....If there was no problem with conflict of interest at the IDSA, why did Senator Blumethal need to launch an anti-trust investigation?
Also, I'm just curious but why can't I donate blood(I have Chronic Lyme Disease and Babesia)? Is that based on the opinions of doctors and or volunteers at the Red Cross? If so, where did they get this idea from? I'm also seriously wondering...if I can't donate blood because I have Chronic Lyme Disease and Babesia...why has my OBGYN not warned me about having more children and passing those infections on to them?

Melissa Ann If syphilis can be passed to an unborn child....why can't Lyme Disease?

Melissa Ann I would like specific answers please! I want to know why. If you know the answer and you can state it anywhere as a FACT....an explanation should not be difficult.

Mary Ladd If you at some point answer any of these questions I have one more. How did you ignore all of the studies Dr. Steven Phillips presented to you in Washington? That alone is pure madness to me.

Patsy Swinson Isn't ANYBODY in the IDSA listening? Doesn't ANYBODY there care at all? Guess not.

Kathie Friedley The IDSA's hold on lyme disease treatment will be remembered historically as a colossal debacle fueled by arrogance, greed, and hubris. Revise the guidelines! Revise the guidelines! Revise the guidelines!

Ian Stark My mother has had Lyme Disease for over 2 years, and those have been 2 years of her life largely spent immobile laying on the sofa. If your guidelines are not reviewed, thousands upon thousands of others will suffer similarly. Chronic Lyme Disease exists, and anyone who denies it is a worm who lied about the Hippocratic Oath.

Meo Doyne Why don't you contact Dr. Waisbren or read his new book for 51 cases throughout his treatment of Lyme Disease? He used to be a fellow of your group, but turned his back from the "dark side" and now believes in Chronic Lyme Disease...

Seth Urguessisasgoodasmine why can't you just accept the FACT that chronic lime disease is real, and it's not like it's a small disease that only affects a few people, it is affecting hundreds of thousands of people, all of whom simply want a cure for the disease that has taken so much of their lives. if you can sleep at night knowing that hundreds of thousands of people are suffering badly because YOU are in denial, then i personally am downright sad to think that i am a member of the same species as you.

Pamela Link Adams Please revise the guidelines for the diagnosis and treatment of chronic Lyme's disease! This disease is now in epidemic proportions and so many are suffering, dying, and going broke trying to receive the treatment they need. Please revise the guidelines and recognize this disease, so patients can get the treatment they so desperately need and have their insurance help cover costs.

Pamela Link Adams Please revise the guidelines for the diagnosis and treatment of Chronic Lyme's Disease. This disease is now in epidemic proportions and so many are suffering, dying, and going broke trying to get the treatment they need. Please listen to these patients and give them the help they SO desperately need!

Gayle Barlow What is going on here? I am the general public, but I personally know of more people suffering from this disease than from any other disease including MS and cancer. These people are young people with a disease that has devastated their lives both physically and financially. We want everyone to hear what is going on and to hear that financial help is being withheld by _________ ...by what? inadequate guidelines from the IDSA, by politics? Let us see some major changes in these guidelines immediately. Let us find out the true reason for these insane policies.

Kyle Rider Your science and medical information is skewed and out dated.Your guidelines are as well. 28 days of antibiotics for Lyme Disease but a year or more for Whipples.

Anne McCracken Chronic Lyme Disease. Please face the facts and revise the treatment guidelines.

Douglas D. Frie Acknowledge Chronic Lyme Disease exists. Until it effects you or one of your family members it will never happen.

Lynn Kay Acknowledgement of Lyme Disease - the REAL truth, not a few antibodics and it's cured, the real story, from people like me who've had it, undiagnosed / misdiagnosed, the REAL affects, how it can destroy your life and kill you. Why does it take a famous person to get the word out, there are plenty of us who have had this HORRIBLE disease and want to spread the word of what it really is about. I challenge you to make it right!

Patsy Swinson I know a woman with all the symptoms of Lyme. She asked me how she could get tested. I told her "Whatever you do, DON'T go to anyone who is a member of the IDSA, or any so-called "infectious disease" specialist". She was understandably perplexed. So are we all.

Susan Christell Dittman I will try to keep this short and to the point. Confirmed Lyme Disease cases are WORLDWIDE, not just a few cases but thousands. If you , the IDSA are serious about your "Mission" statement, then I must ask why Lyme Disease is treated as it is?

Kenneth Poindexter Of the 2100+ comments, over 1363 of them contain the word "lyme". Over 500 of them contain the word "chronic". Does this indicate that "chronic lyme" exists?

Kenneth Poindexter Patsy Swinson Make sure you tell her to ALWAYS look for the FIDSA that they put in their list of titles and if you see it, RUN. Just because a doctor is an infectious disease specialist doesnt mean they are part of this society. There are good ID docs out there. Just got to look for the ones that dont support the society and are open to the facts.

Grace Wollert Change the Lyme Disease guidelines - stop and prevent suffering and pain! Educate Doctors so they can treat patients.

Stephanie Michelle Kealy sooo are you just going to block all of us from posting on this site?

Lisa Dungan Roth *An honest review of the Lyme Disease Guidelines looking at the science presented at the IOM (Institute of Medicine Committee) workshop and acknowledging that all is not known about this emerging complex disease with its many co infections.*

Susan Christell Dittman I would ask that the IDSA develop a protocol that addresses helping and educating those who suffer from Lyme Disease as well as those in the medical field. Thousands have been spent on HIV & Cancer research & education. Lyme seems to be forgotten. Personally my family has spent thousands on trying to deal with the disease with no real help or direction from the medical field. This is not a disease brought on by lifestyle, genetics,or poor choices. It is simply caught by having an infected tic decide to attach itself to your UNLUCKY body. HIV, Cancer and most other diseases are covered (at least in part) by insurance...not Lyme. Why? Physicians seem at a loss as to what they understand and how they will be allowed to treat the patient. Is this a way to "improve patient care and health"? I would really like someone with IDSA to give a full explanation. This is not a disease that is going away, it is growing and if you did your job you could actually be applauded for saving lives instead of helping cause the losses or side affects that, by the way, cost the patient & the insurance companies more in the long run.

Kellie Starkey Petrick A fair, reasonable and ethical treatment of Lyme which even the CDC calls it the country’s fastest growing infectious disease needs to come MORE TO LIGHT

Kim DeSantis Goodwin Your guidelines are ruining families, destroying lives and leaving us in a hopeless state of tortured pain. Please care about people and do your job. My goal in life is everyday to help others. Our csildren, husbands, wives, mothers and friends are all in your hands to finally be honest. Moving forward not even the years we all lost of our lives just dont take anymore days away. Dont let people think they are crazy and have some stupid post lyme made up thing. Unless you have had this nightmare illness you dont know how wrong you are. If you watched your child screaming at night that they want to die from the pain and your heart is broken and your so so sick you cant even stand yourself either.

Do you even research the suicide going on from this. The deaths with lyme disease actually listed as cause of death and the addictions from the pain medicine never being enough to even take the edge off the pain. The two people in the picture to the left are real and i gave lyme disese to that beautiful little girl and right now i am laying next to the man i love while he had to take sleeping medicine, anxiety medicine and melatonin with pain medicine to sleep his first time in 3 days. He is still shaking his hands from the tingling and pain in his legs and hands. He was born with a heart condition and this illness has hurt his valve more. One full year now of treatment and he is so much better most of the month but in no way is it gone. There is so much involved with this slow recovery process. My lyme dr saved my family when dozens of drs failed us. My life turned upside down mother of 5 so i cant lay in bed but i am in tears trying to have them live a normal life and not just remember mom is sick. When im home i lay down falling asleep sitting up and the pain is everywhere 10 months into treatment and i can see better now, my brain fog is lifted, my flu symptoms are only a week of the month on average, cold and hot sweats so much better now after treatment for my co infection babesia. I am seeing the light but still no way would i be ready to go off antibiotics. It would all come back and i would lose another 6 years. Nobody should ever have to start treatment over after all the hell they have been through. We are real and our cries for help are filled with pain. Please listen

Cheri Coussan Wonder who you'd want to treat your mom, wife, sister, daughter, brother, son, loved one if it turned out their fatigue and depression of a few years was actually Lyme!?! Member of IDSA or ILADS? This is nothing short of discrimination. By way of your archaic guidelines people are unable to get assistance from the insurance companies that are supposed to help a claimant mitigate costs. Disgraceful.

Karen Smith And yes - if you read / click on my name...... I am an Aussie - So why do IDSA guidelines matter to me??? Because they affect thousands and thousands of people worldwide.... The IDSA guidelines have managed to bring people worldwide together to fight the inhumane suffering that the ignorance of research brings about..... The Lyme guideline authors have it covered - two of the authors are from Europe (Stanek and Styrle) and ensure that the same message is adhered to over in Europe....... Then you have the HPA ; Health protection agency in Europe - whose "independent review" states that ILADS guidelines shouldnt be used..... Funny that O'connel with the HPA in Europe - and writes articles with the same IDSA Lyme guideline authors...... So flawed IDSA treatment guidlelines have meant that the whole world suffers for the greed of a couple of dozen individuals... The IDSA should stop backing these individuals - read the facts and scientific findings yourself - and demand the right thing be done!!!!!

Lisa Dungan Roth "An honest review of the Lyme Disease Guidelines looking at the science presented at the IOM (Institute of Medicine Committee) workshop and acknowledging that all is not known about this emerging complex disease with its many co infections.

Sarah Silver Your Lyme Disease guidelines urgently need changing, so many people are going through hell because they've been misdiagnosed or given just four weeks of antibiotics which would only treat a very early infection. Doctors are afraid to treat aggressively for fear of losing their licenses and patients are suffering and dying. Please do something, IDSA. The truth will come out in the end, you will surely come out of this better if you change your guidelines sooner rather than later and before it becomes massive news in the press, which is bound to happen one day.

Birgit Jürschik-Busbach Like Dr. Burgdorfer has said: It's a shameful affair.

Edyta Gałęziowska IDSA---> look at summary:http://www.tvmed.pl/tresci/6764/Falszywie-ujemne-wyniki-testow-serologicznych-w-kierunku and page 102:
http://books.google.pl/books?id=VnbOKWQHOD0C&pg=PA97&lpg=PA97&dq=%22kompleksy+immunologiczne%22+++borelioza&source=bl&ots=5wIDiGIBUQ&sig=MHVrq_vCJlY4Pbw7AjsMJ2yYYAQ&hl=pl&ei=hTXpTbPNH4OWOvvh1bEB&sa=X&oi=book_result&ct=result&resnum=2&ved=0CCoQ6AEwAQ#v=onepage&q=%22kompleksy%20immunologiczne%22%20%20%20borelioza&f=false

Bonnie Kostiuk Gosh, I dont know where to begin but Ive read enough comments to cover what I want to say. Doctors need to be encouraged to treat Lyme ASAP for however long is needed via patient symptoms-requests.

Valerie Woods So many of my friends and family members are suffering. Some have had their lives devastated. Change the guidelines!

Robin Gunn The IDSA Lyme treatment guidelines are a disservice to your profession and your patients. The guideline panel is keeping IDSA doctors ignorant and fearful to treat Lyme. A vast amount of basic scientific and physiology data is ignored in the guidelines.

Robin Gunn I try to understand the motivations of the in reality small number of doctors that built this idsa house of cards Lyme guidelines. Is it medical insurance companies? That's complicated. Surely there are many people with untreated/misdiagnosed Lyme who cost their medical insurance companies a lot more money than the cost of IV antibiotics. It's possible that enough people with Lyme lose their insurance and/or the energy to fight for care to keep it profitable. I think it's something else... I think for individual IDSA doctors, it's fear of malpractice. The guidelines protect them against a Lyme lawsuit. Furthermore, our honest requests just confirm their suspicions (and what they've been told) that lyme patients are crazy & demanding. For the guideline authors I think they are motivated by something more than money- ego. They have built large careers on bad science. In academia PhDs & MDs would rather die than admit they are wrong anything. These trenches were dug long ago. It's unlikely they will ever come out. Lyme patients- I think we are just talking to each other on their page.

Kaethe Mitchell The sun is up, it's a beautiful, though cold, day. 29 degrees and no snow. The ticks will freeze in this weather, I think. No blanket of snow to protect them until the next warm day where they will emerge to bite another creature. But why am I really writing right now? Upstairs my daughter is crying in bed because she wants to go to school, but is too sick today, and was home yesterday as well. She is not making up her symptoms to avoid school and life. She is not experiencing the aches and pains of daily life at age 14. She made the JV cheer squad this fall and was asked to compete with the Varsity thanks to her ILADS LLMD getting her well. But she is not well enough yet to know with confidence that she can wake up feeling good every day like she did, years ago, when she was healthy, back before she had to give up everything when her world came crashing down with neuroborreiliosis, bartonella and babesiosis. She is strong and determined, but this disease knocks the strong and determined on their glutei maximi. If IDSA's guidelines were not so restrictive, she would not be in this shape. It is time to change them. What are you waiting for? Our young people are the future and their lives are being stripped away by a lifetime of illness. Illness that can be prevented.

Bill Klavonski I'd like to know why teenagers with ACNE can be on open ended ABX treament, while we Lyme patients are told, 30 days and you're done. Really? So, zits are more important than this terrible disease? Where is the worry about ABX being over prescribed when it comes to ACNE? Limit their ABX and you'd see people pitch a fit. Lyme? No big deal, right?

Bill Klavonski Time to stop talking to ourselves here. We've got to get this out to the media, NOW!
January 11 at 9:30am · Like · 13

Carl Tuttle Please view the following letter addressed to the Director of the CDC, Fort Collins
Nov 27, 2011

CDC Office of the Director
3150 Rampart Rd
Fort Collins, CO 80521
Lyle Petersen MD, Director

Dear Dr Petersen,

Thank you for taking the time to respond to me directly regarding my letter to Secretary Sebelius concerning faulty Lyme diagnostic tests. Those of us who have been harmed by the two tier testing algorithm find it a conflict of interest when the Director of the CDC "strongly recommends" only FDA-approved antibody tests for the diagnosis of Lyme disease especially when employees of the CDC (Barbara Johnson) hold patent interests in these faulty tests.

This is not the first time Lyme test reliability has been questioned and patient experiences (case studies) ignored. Studies have proven that these tests are utterly useless while the CDC continues to deny any problem.

Advanced Laboratory Services Borrellia culture test has proven that persistent infection or "chronic Lyme" does in fact exist.

The letter below sent to the CDC's Financial Management Office and copy to Secretary Sebelius is petitioning the wasteful Lyme disease studies funded by the CDC. I searched other Lyme studies through the NIH RePORTER portal and found most other Lyme studies were funded by NIAD, NCRR etc. but no others funded by the CDC.
http://report.nih.gov/rcdc/categories/ProjectSearch.aspx?FY=2008&ARRA=N&DCat=Lyme+Disease

I found this quite odd…… Is this collaboration between the CDC and the Wormser denialist camp?

Sincerely,

Carl Tuttle
Hudson, NH
Website:
http://home.comcast.net/~runagain/site/?%2Fhome%2F

Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-lyme-disease

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Eran Nils Redick *Was the cause of the Lyme CT outbreak directly related to research on Plum Island on biological weaponry? Fully supported by the US government?*

This is not the first time Lyme test reliability has been questioned and patient experiences (case studies) ignored. Studies have proven that these tests are utterly useless while the CDC continues to deny any problem. Advanced Laboratory Services Borrellia culture test has proven that persistent infection or “chronic Lyme” does in fact exist.

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Carl Tuttle
Hudson, NH
Website:
http://home.comcast.net/~runagain/site/?%Fhome%F

Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-Lyme-disease

Daniel Armstrong My wife went undiagnosed for approx. 16 yrs...after being misdiagnosed as having everything under the sun a precious MD we were lead to finally dx'd Lyme....that was three years ago. She has missed out on soooo much and daily struggles to "push through". What if the guidelines were different, that doc's actually had best practice guidelines from trials and case studies from doc's actually fighting this disease and winning. Things would be different for my wife and for my precious 4 year old daughter...who is being treated for Lyme disease for the second time in her life. My daughter was when she tested positive for Lyme....she contracted it in utero or through breast milk...before you say..that's impossible..what do you think the lihood of a one year old being bitten by a tick out in the woods would be??? Things would be different...we would not be rubbing my daughters legs every night before she goes too bed and in the middle of the night because she is screaming that her legs hurt and her legs won't stop "squirming around"...my wife and I would never have had to have a discussion a year and a half ago...planning that she would not be around due to how sick she was.. and what I needed to do with our daughters future without a mother. IDSA...you can choose this day to make things different for millions of people. Set best practice guidelines according to the empirical evidence in trials, and listen to practioners who are actually treating Lyme and winning. Thank You for your time.

Tim Lamb *The IDSA Lyme committee kicked off one member who disagreed with the consensus on the treatment guidelines so they could have a unanimous approval and the chair resigned but the IDSA allowed this. The elisa / western blot screening diagnosis was instituted in a period where the CDC perceived an over diagnosis and over treatment. Now we have under diagnosis where medical professionals consider symptoms psychosomatic and don't even run a Western Blot to see if there has been exposure to the Lyme bacteria.*

Melissa Rascio Bill Klavonski - some antibiotics will never be used or needed for serious infections that why my rheumatologist said it was ok to give me minocycline long term for RA (WHICH I KNOW IS NOT REALLY RA!!!) but that was his reasoning.

Amanda Blaker Wow, IDSA please tell me how these thousands of comments from living individuals who all suffer from Lyme Disease are all wrong. We are wrong right? We are in debt in the thousands, take a plethora of meds, have been to dozens of 'specialists' and were diagnosed with BS rheumatology auto immune diseases that AREN'T REAL! Lupus? Really? That word is a big excuse for 'we don't know'. You should be ashamed of youselves, you are supposed to help people through scientific data and you aren't.

Lorri Carey Please revise the medical guidelines defining treatment options for Lyme Disease. People are suffering and need the practical medical support of the IDSA and insurance companies which has been denied to date.

Tiersa Buckley How about starting with the IDSA and insurance companies acknowledging the fact that "Chronic Lyme Disease" does indeed exist and that alot of sick people out there is your proof that sometimes 30 days of antiobiotics are not enough! Doctors need to be treating patients correctly and hitting the Lyme hard as soon as its diagnosed!

Carolyn Jean Cronce-Armstrong The guideline for Chronic Lyme Disease need to be changed. I have been watching my daughter- in- law and now my 4 year old Granddaughter suffer with Lyme and there is nothing I can do but love them and prayer for them. YOu have a chance to change the lives of many people that are suffering and let the drs. treat them longer.

Eran Nils Redick I was treated based on symptoms for Lyme disease, a test taken at that time indicated I was in fact positive for Lyme. Some time later after I felt better and went through the course of antibiotics I tested positive for Lyme again another round of antibiotics.

Now the test comes back negative. I must be cured now correct? I mean the tests are highly reliable and I should not worry or be retested correct?
One doctor told me I must have been bitten on two separate occasions that was why the double positive, sure, why not.

Eran Nils Redick Was the cause of the Lyme CT outbreak directly related to research on Plum Island on biological weaponry? Fully supported by the US government?

Cam Altee Brown I wish every member of the IDSA would take the time to read "Cure Unknown" by Pamela Weintraub a leading medical journalist. http://www.cureunknown.com/

Sara Connor
http://www.youtube.com/watch?feature=player_embedded&v=LOXNlCW

Donna M. Cutillo I have developed a close relationship with a Lyme Disease patient and I have read extensive information on Lyme because of her. As a professional in the health care field for over 30 years, I find it extremely sad and quite disturbing how the IDSA responds to obvious and real facts brough to them by Lyme patients which the IDSA continues to ignore. PLEASE open up your minds and hearts to lines of communication, via listening, to these intelligent human beings who live with this disease on a 24/7 basis. Thank you.

Sara Connor Founding member of THE IDSA HAS A NEW BOOK !
Chronic Lyme does exist !

Sara Connor We should read this book
because we know the IDSA won't.

Sara Connor Let's see if for real !

Sara Connor If our Doctors from ILADS wrote anything what this book is suppose to be about,
they would have a lot of trouble coming their way.

Sara Connor Burton Waisbren, MD, FACP, FIDSA has been practicing medicine for over 57 years. He is one of the Founding Members of the Infectious Diseases Society of America (IDSA) and has published research on Lyme disease in prestigious journals such as The Lancet.

Dr. Waisbren is a native Milwaukeean who received his B.S. and M.D. degrees from the University of Wisconsin Medical School in Madison, Wisconsin. He served his internship at the Harvard Service at Boston City Hospital. His military service was at the Navy Medical Research Institute, Bethesda, Maryland and the Biological Warfare Center, Camp Detrich, Maryland.

His residency and fellowship was served at the University of Minnesota Hospitals where he was an instructor in the medical school. He received a master's degree in bacterial genetics from the University of Minnesota in 1951. He moved to Milwaukee, his hometown, in 1951 and established a private practice in internal medicine, infectious disease and immunology. At that time, he also headed the infectious disease control unit at the Milwaukee County Hospital.

From 1951 to 1969, he was the director of the infectious disease division of first the Marquette Medical School and then the Medical College of Wisconsin. During that time, he was appointed associate clinical professor of medicine. He was the medical director of the burn center at St. Mary's Hospital from 1962 to 1982. He has directed a cancer immunotherapy clinic in Milwaukee since 1973 . He has published numerous articles in the peer reviewed medical literature and has authored books on systematic methods of critical care and on medical emergencies.
Dr. Waisbren is board-certified by the American Board of Internal Medicine and also is a fellow of the American College of Physicians and the Infectious Disease Society of America. He is a founding member of the Infectious Disease Society of America, the American Burn Association, and the Critical Care Society of America.

Cathie Smith We are all suffering from similar symptoms after being bitten by a tick. We need to be able to work with infectious diease specialists who have an open mind in order to sort this out. We are in agony with very little help and we and our families are affected greatly. We are palliative until you are willing to work with this population.

Jolene Offenbecker Please review and change your guidelines for chronic Lyme disease! Recognize that chronic Lyme exists. Consider best practice and clinical studies to determine what is best for those who suffer with this disease, NOT the interests of big money and pharmacology.

Kate Scott I would like to see the IDSA review and revise the guidelines for treating Lyme and Chronic Lyme Disease. It's time to put an end to the ignorance!

Tim Lamb The IDSA Lyme committee kicked off one member who disagreed with the consensus on the treatment guidelines so they could have a unanimous approval and the chair resigned but the IDSA allowed this. The elisa / western blot screening diagnosis was instituted in a period where the CDC perceived an over diagnosis and over treatment. Now we have under diagnosis where medical professionals consider symptoms psychosomatic and don't even run a Western Blot to see if there has been exposure to the Lyme bacteria.

Rachel Groom Please revise the medical guidelines defining treatment options for Lyme Disease. People are suffering and need the practical medical support of the IDSA and insurance companies which has been denied to date.

Logan McCulloch How about educating local Docs that Lyme is present ALL across the US? I was infected in a National Park in my state. But because of the ridiculously narrow CDC reporting guidelines my case won't be reported to the CDC. My family Doc missed my classic Lyme rash, and later when I suggested Lyme (I was bitten by 20+ deer ticks) I got the "there are virtually no confirmed Lyme cases in KY"). So there is no way to get park officials to warn other families visiting this hugely popular NP that they and their children are at risk for Lyme. Why is it that every state contiguous to ours has proportionately FAR more CDC confirmed cases of Lyme than KY. Obviously it's not being considered nor diagnosed due to IGNORANCE. Birds, deer and small animals seem to freely cross state lines...

Heirloom Hourglass Why don't you read this written by one of your own? http://Lymebook.com/burton-waisbren-chronic-Lyme-book-essays

New Lyme book by Burton Waisbren - BUY IT HERE - Treatment of Chronic Lyme Disease, with Essays Lymebook.com
Order your copy of Insights into Lyme Disease Treatment by Connie Strasheim.

Kristen Meli Martinez Yep- you can pass it in utero, 2 years after treating the mother with 3 months of antibiotics. And blood tests aren't always accurate. My 6 month old daughter 's brain tumor was positive for the DNA of the Lyme spirochete, but her blood tests were negative.

Kim DeSantis Goodwin yup my daughter is positive too and I was symptom free didn't know I had anything wrong with me. Her blood test came out negative urine test positive. Then after 5 months of treatment for months blood test positive.

Mary Shaffer I live in southern MD, infamous LYME area. Numerous tick bites, one with a 'small' bullseye rash. Despite repeated requests (with onset / worsening symptoms), my primary care physician never wrote my blood tests up for Lyme tests ... fast forward years later, finally got the order for Lyme test .. no surprise it was positive. Several weeks of anitbiotics, no change ... retested, another + test, primary care doc told me "dont worry it's just Lyme" ... left that doc, who had been my PCP for over a decade ... second PCP, saw test results ... NEITHER reported me as having an infectious disease! That didn't happen until another year later, after I found a physician that knows what LYME is .... LYME is grossly UNDERREPORTED!

Kristen Meli Martinez And she never went camping with us or walked in the woods- she was born in TX but I was infected two years beforehand in CT: adequate treatment could have saved her from this.

Lori Sample MacGregor Your Lyme Disease guidelines urgently need changing, so many people are going through hell because they've been misdiagnosed or given just four weeks of antibiotics which would only treat a very early infection. Doctors are afraid to treat aggressively for fear of losing their licenses and patients are suffering and dying. Please help us.

Stephanie Vandagriff After 2000 comments, the only response we get is a bad letter denying all our claims. What will it take to get an actually, genuine response from you. Picketing the IDSA headquarters?

Stephanie Vandagriff Even discover magazine validates us. http://discovermagazine.com//jan-feb/

Jen Klee An update in the guidelines on Lyme disease. That will acknowledge that the pain and suffering I've been going through for years is actually real so I can get real treatment for it. I've been on continuous antibiotic treatment for over a year now and it IS working! Denying that chronic Lyme exists doesn't make all of us who're suffering go away.

Paula Gallo Here's a good one for you all.
http://www.kettmann.com/Lyme/Save/Chronicle%-%Ticked.mp

http://www.kettmann.com/Lyme/Save/Chronicle%-%Ticked.mp
www.kettmann.com

Peninah Ann www.cureunknown.com by science writer, Pamela Weintraub--when will IDSA help us?

Billy Batson Give us a fair chance.

Rachel Gerein Please review your current testing and diagnosing procedures regarding Lyme disease in Canada. My friend has been diagnosed and is desperately ill. Unfortunately, the hardest battle for him to date is not having access to treatment in Canada. Too tough to even imagine.

Wendy Vogt January Discover magazine article - "Chronic Lyme Patients Validated". You cannot ignore the facts.
http://discovermagazine.com//jan-feb/
Expand Preview

Brittany Goff Dear IDSA, please go outside and expose yourself to a deer tick that carries Lyme disease. Don't treat yourself for at least months. Then, take a few weeks of doxy and report to us how you feel........if you haven't killed yourself by then.

NIH Research Portfolio Online Reporting Tools (RePORT)
- RCDC Project Listing by Category
report.nih.gov
Affiliate links of U.S. National Institutes of Health (NIH).

Angel Williams Spell was told day before yesterday....that because i live in NC that i cant receive IV therapy even though i have proof that oral antibiotics is a little harsh on my tummy.....MY doc even said i would be better off on IV but insurance wont pay for treatment past days because of cost...but how much is it going to cost to have a new stomach ? or the treatments to fix my stomach?.....and responding to the ACNE treatment of open ended doxy treatment for zits.....but u limit us? i know three people on doxy for acne and said their doctor told them as long as they have acne...they can be on doxy....WHAT?...and u tell us days and we should be healed?....im sick of liars cause common sense will tell you that isnt right...and you lie when u say u have no interest in what you are denying us....A BLIND MAN COULD SEE YOU HAVE FINACIAL INTEREST.....

Scott Reed In the last 30 years, blood transfusions caused at least 159 cases of babesiosis... See full article from CDC report at http://discovermagazine.com//jan-feb/

Dianne Vogt *. . . . There are PLENTY of intelligent doctors who disagree with your antiquated guidelines and they are being ignored just the patients who they are unable to treat effectively.*

Lab tests are unreliable and a large majority of people with a diagnosis of fibromyalgia, chronic fatigue syndrome, MS, and many other similar misdiagnoses actually have Lyme Disease but they don't know it so they're not getting the treatment they need right from the beginning.

Gretchen Ahlers One factor in deciding upon IV therapy vs oral antibiotics has to do with the level of penetration into the brain. Orals are not as effective in doing that. If the infection is in the brain, it would seem to be good practice to penetrate the brain as fully as possible. Lyme Times has an old article making the case to insurance companies regarding IV Rocephin for neurological Lyme. This may seem like a conversation between us who have Lyme, but the topics that are raised here are germane to the issue of guidelines. Again, the insurance company by definition is supposed to refer to an appropriate specialist and render the extent of treatment necessary. That is why we pay insurance....in case we get sick and need costly medical care. Inappropriate guidelines give the company a chance to deny. With what other disease affecting the brain would such a blase attitude prevail?

Hannah Hollingsworth
http://discovermagazine.com/2012/jan-feb/90

Liz Karkoff A new study uncovered biomarkers for Lyme disease symptoms that persist even aft...

Amy Schultz Milnes It's hard to believe that after all this time, a person who walks in to a doctor's office today with a bulls eye rash, may (or may not), walk out with a prescription for two weeks of antibiotics and most ly a life sentence of debilitating pain and suffering. However, most won't even be that "lucky" and will go undiagnosed for years as a result of your antiquated "guidelines". Testing is unreliable and your guidelines don't cure Lyme and co-infections as evidenced by all the people who have posted here and suffer every day of their lives. The sad thing is that you know all of this. How can your society continue to ignore this any longer? It's also hard to believe that testing and treatment today is the same as it has been for decades, no advances from "the experts"?

Jennifer McNeill Wallace We are not looking for a statement from you...we want a PLAN OF ACTION now! The last time I checked, I knew...let me see...ZERO people with tuberculosis! I have at least 20 in my neighborhood alone with Lyme disease. We are infested with ticks here in North Carolina. There are so many new tick bites every spring, summer and fall here...and even in the winter. Everywhere I go, I meet someone who has a loved one or knows someone affected by Lyme disease or has the disease him/herself. Even my dermatologist and cardiologist in Raleigh, NC agree with my Lyme Dr. and what he is doing to get me well -- prescribing long-term antibiotics. They say they've seen other patients who have been saved by long-term antibiotics.
A recurring theme here (medical/clinical evidence) would be that long-term antibiotics are working! And

since you all are not doing anything new to find a better cure, we have to take what is available to us to get better (if we are lucky enough to get treatment). I have nothing but support from my cardiologist, dermatologist, pediatrician, primary care physician and other doctors I've met in the ER and along this awful journey. They tell me they are seeing more and more people devastated by Lyme disease here in North Carolina. And guess what? They are all absolutely dumbfounded by the lack of interest, support, and research by the infectious diseases doctors, esp. since this is your speciality!

My cardiologist said to me "one of my patients cannot receive treatment here in NC and she is so sick and you are having to go out of state. What in the world is going on?" My dermatologist probably knows more about babesiosis than you do! He is also a professor at a very reputable college here and is teaching his students about it! He said I have a rash on my body that is consistent with a bartonella infection. He is a dermatologist...not an infectious disease specialist! He said "I am seeing more and more acquire this disease right here on our golf courses." Do you know anything at all about the multitude of coinfections that you can acquire with a tick bite? What about all the viruses that take over our bodies when our immune systems shut down? Have you researched anything at all? You are being left in the dust by doctors who actually care to know more and want to learn, help, and discover. We want more from you than a one paragraph statement. We are sick and dying! Your response was unacceptable.

Wrblr Fvtwlv IDSA - what a pathetic response. The Lyme Review panel was unbiased - really? Chaired by an ex-president, winner of a special award, who said straight out during the review that her and fellow panel members don't like the interference of politicians, basically thumbing her nose at Blumenthal. "Doctors" Steere and Wormser - how would they benefit from treating with long-term Abx? Steere told Sen. Kennedy he never saw any long-term neurological cases; during the panel review, it was said these only exist in Europe. What are all those proteins UMDNJ found in the spinal fluid doing, having a disco dance?

Melissa Jason The IDSA deleted and BLOCKED Brittany from this website. you cowards!!!!

Dave Bassett I would like every member to get bitten by a tick.

MiJin Nam Liu Revise your guidelines re: Lyme. Too many people are needlessly suffering. What if it were your child, mother, spouse or loved one suffering?

Michelle Newell FDA approves bill that deregulates antibiotic use in animal feed and the IDSA is afraid that human use of antibiotics will lead to super bugs? http://www.guardian.co.uk/world//dec//fda-u-turn-antibiotics-animal-feed

Michelle Newell Come on IDSA, we are sick and dieing of Lyme disease and there is no proof that waiting to find the auto-immune function of Lyme disease in order for a valid treatment to be created. Look, we are sick and it's sick that these guidelines limit doctors ability to use sound scientific data, on what we do know, to treat their patients. Listen to ILADS and other valid research and create guidelines that actually help people.

Courtney Lynn I dont know how any one you sleep at night!

Courtney Lynn Any of you*...friggin Lyme brain..ugh i hate you IDSA!

Peggi Mauney My friend's mother died from complications of a tick bite. Must my son die, too? Must I, at nearly 70 years old, go broke from spending the money for the long trip to see a doctor, doctor's fees, lab expenses, and medicine? Must I take my son to Mexico for treatment? WHY do I have to spend the money? Because he is young with a family to support, and he is often too sick to go to work! I want him to be able to see his children, now 4 and 6, grow up.

Dianne Vogt CHANGE to Lyme Disease guidelines: Millions of people me are suffering from this disease and we're becoming disabled, treated like we're crazy, and ignored by the government agencies that create the guidelines for treatment.

Kenneth Poindexter . . . . *Most MDs don't know that borrelia produce a large variety of toxic bacterial lipoproteins (BLPs) and they aren't familiar with the way these BLPs cause disease. Lyme disease specialists must use very keen clinical judgment when diagnosing cases of Lyme disease. In defense of the ignorant physicians, much blame can rest on health officials and the medical establishments that are not giving clinicians the appropriate information they need to diagnose these difficult cases of Lyme disease. The criteria being used to report Lyme disease by physicians is often set by state health officials and is often based upon the rigid criteria established by the Centers for Disease Control and Prevention (CDC).*

Chronic Lyme Disease exists, it's not all in our heads, we're not crazy, entire families are infected through pregnancy, sexual transmission, breastfeeding, etc.

There are PLENTY of intelligent doctors who disagree with your antiquated guidelines and they are being ignored just like the patients who they are unable to treat effectively.

Lab tests are unreliable and a large majority of people with a diagnosis of fibromyalgia, chronic fatigue syndrome, MS, and many other similar misdiagnoses actually have Lyme Disease but they don't know it so they're not getting the treatment they need right from the beginning.

Not all Lyme Disease sufferers ever see a bulls-eye rash or have any other symptoms so they don't always become ill at first. It may take something, pregnancy, stress, or some other jolt to their system for the actual Lyme symptoms to show up.

Then they go for years, from doctor to doctor, trying to find out what is wrong with them. There are only a handful of labs in this country that do accurate testing for tick-bourne diseases and most of them are not covered by insurance.

Those of us who have done our research and know we have CHRONIC Lyme Disease cannot get proper treatment for our illness due to blocked treatment guidelines that desperately need to be changed.

I am an intelligent person who is FRUSTRATED and dependent on narcotic pain medications because that is the only treatment I'm allowed to receive by my doctor due to your guidelines.

Doctors don't want to lose their licenses so they're forced to watch their Lyme patients suffer. I am one of those patients and I want my life back!

I want to be able to watch my grandchildren grow up and I want to have the strength to drive to visit them.

I don't want to be on SS Disability because I'm broke and I had to give up on my pursuit of a college degree when I got too sick to continue my classes.

If I had gotten a correct diagnosis of Lyme Disease, along with proper treatment, in 2003, I would now have a college degree and a good-paying job.

This travesty is part of the reason why our Social Security system is going broke!

We don't want to be sick. We want you to open your eyes to this subject and make the necessary changes to the treatment of Lyme Disease patients.

We, as a group of physically disabled people, of all ages, and all parts of the country and the world, are suffering needlessly.

I know you've already seen all the facebook posts on this subject and your response is UNACCEPTABLE!
We deserve respect, recognition, and most of all, CHANGE!

Did I make myself clear?

WE NEED CHANGE!!!!

Stop ignoring us, do what you KNOW is right, listen to the doctors who are so desperately trying to get these changes made to the government Lyme guidelines. Then, AND ONLY THEN, we will stop pushing for CHANGE.

Deborah Via Dixon you deleted my post? How dare you! You will see that the Lyme community will not be quiet. I see a revolt in the near future. The changes must be made. It's the humane thing to do.

Jason Harrington I read the response from Diana Olson back to the LymeDiseases.org question on what they think about all of the comments about the guidelines being posted. And I also believe that the recent review of the guidelines was not really close to an independent panel of medical expertise. It would be independent if there were new people doing the review, not nearly the same who drafted the first set of guidelines. The current set of guidelines appear to be biased to protecting medical insurance providers and stopping doctors who are on the front lines fighting this growing issue from being able to use all the "tools" to help people recover some what they life. Try not to be the blockaid to treatment and research or the puppet of corporations.

Carl Tuttle Please view the letter below sent to Health and Human Services Secretary, Kathleen Sebelius:

December 6, 2011

The U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201
Attn: Secretary Kathleen G. Sebelius

Dear Secretary Sebelius,
I meant to include references to the studies that have proven the Lyme ELISA test unreliable. Here are three references below and an attached page of studies presented to the New Hampshire Department of Health as a follow-up to our Lyme Discussion Meeting, Aug 18th.
http://home.comcast.net/~runagain/Dept%of%Health%Agenda.pdf
1. A two year study out of Johns Hopkins concluded these tests were less that 50% accurate. A screening test by definition should be 95% reliable and we're not even close to that number.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC/

2. The College of American Pathologists found that the ELISA tests do not have adequate sensitivity to be used as a screening test for Lyme disease. In two blinded studies that tested laboratories accuracy, the ELISA failed miserably. In the latest study by the College of American Pathologists, 516 labs were tested. The overall result: 55% inaccurate! (Bakken 1997).

3. Lyme disease researcher and physician, Dr. Sam Donta of Boston University Medical Center reported that 52% of patients are negative by the ELISA, but positive through the Western Blot. (Donta, 2002). Because of this, the best antibody test to use for diagnosis is the Western Blot

4. Please see the attached Word document for additional studies.

Per the Lyme discussion in August our faulty two tier Lyme test algorithm has caused great harm to US citizens and continues to do so. The CDC is acting as an autonomous group where its authority is absolute and cannot be challenged. They answer only to themselves. We are experiencing the devastating effects of denial while the federal government chooses to deny the Lyme epidemic exists. If it is to continue, then the authorities will have to come up with some rational explanations to explain this irrational behavior.

Sincerely,
Carl Tuttle
Hudson, NH 03051
Website: New Hampshire Lyme Misdiagnosis

Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-Lyme-disease

Phyllis Shaw This is from a new post on Lymenet, the premier source for ILADS treatment information & guidelines.

Kenneth Poindexter Physicians frequently overlook cases of Lyme disease simply because they don't know the complex pathogenesis of the disease. They don't understand that Lyme disease causes well over 100 different symptoms; the common arthralgia (the medical term for joint pain) is a LD symptom that most physicians are familiar with; however, it is only one of many symptoms caused by Lyme disease.

The clinical presentation of Lyme disease can be very subtle and complex. Most doctors don't know that laboratory tests are often useless and misleading. Results are frequently negative or inconclusive in individuals with borreliosis. The technology we have to deal with borrelia species is in need of significant improvement. The isolation and identification of borrelia is rarely successful; and no clinical laboratory test exists that can definitively diagnose Lyme disease.

This is why a diagnosis of Lyme disease is heavily based upon clinical information such as history, symptoms, and response to therapy.

There is an art to medicine when dealing with Lyme disease. Lyme experienced physicians must use keen clinical skills and judgment when dealing with suspect Lyme disease patients. They thoroughly evaluate the patient's history and symptoms when seeking a diagnosis and are able to recognize even the subtle symptoms of complex Lyme cases. Most physicians don't recognize the symptoms of chronic Lyme disease and will rely solely on laboratory tests to confirm a diagnosis. Frequently these lab tests are negative and mislead the physician and patient to search for another cause.

Most MDs don't know that borrelia produce a large variety of toxic bacterial lipoproteins (BLPs) and they aren't familiar with the way these BLPs cause disease. Lyme disease specialists must use very keen clinical judgment when diagnosing cases of Lyme disease. In defense of the ignorant physicians, much blame can rest on health officials and the medical establishments that are not giving clinicians the appropriate information they need to diagnose these difficult cases of Lyme disease. The criteria being used to report Lyme disease by physicians is often set by state health officials and is often based upon the rigid criteria established by the Centers for Disease Control and Prevention (CDC). This CDC criteria was established for an epidemiological survey, which was designed to study the distribution of Lyme disease. The two-step method of the CDC uses a screening immunoassay for all patients followed by a more sensitive and specific Western blot only if the screening test was positive. Unfortunately, this approach was originally intended for surveillance of Lyme disease in potentially asymptomatic patients, not for diagnostic purposes in patients with symptoms that are potentially related to Lyme disease.

This criteria was not intended to be used as a standard for the clinical diagnosis of Lyme disease; the CDC has clearly stated this. Unfortunately, ignorant health officials and physicians continue to use these criteria for the clinical diagnosis of Lyme disease.

Kenneth Poindexter
https://www.facebook.com/note.php?note_id=
My Lyme Story
Lyme disease is very misunderstood. There is so much controversy surrounding i...
By: Kenneth Poindexter

Jeannine Comtois Bennett Please, please rewrite your guidelines and consult with ILADS Doctors who are actually out there in the trenches working with Lyme patients and getting results.

Brian Silva
http://www.Lymedisease.org/news/touchedbyLyme/idsaresponse.html - I lived on our dairy farm for over 20 years and can clearly recognize what drops out from under the bull's tail. The above link brought back some memories of those days. /;^> -b, !Bb

Laura DeCoste Ok so let me get this straight. According to idsa, there is no such thing as chronic Lyme disease. Yet if Lyme is left untreated, it could be fatal. Uhmmmm DUH! U medical doc's r so smart. Tell me, does 1+1 still equal 2?

Catherine Collins From a study published two days ago by Embers, Barthold et al, seems monkeys show persistant infection! "Persistance of Borrelia burgdorferi in Rhesus Macaques following Antibiotic Treatment of Disseminated Infection"
http://www.plosone.org/article/info:doi/./journal.pone

Liz Karkoff I have it on good authority that 2 individual IDSA members are sending their family members to ILADS doctors for Lyme treatment, why is that? If IDSA doctors think that their Lyme guidelines are so great, why go to an ILADS doctor who disagrees with those said guidelines?

Kara Morgan I would to see myself have a very comfortable day without being in pain because of your Lyme guidlines. I would like a cure. You don't want us to take long term antibiotics than we need a cure, money to do testing and there of course is a better way than long term antibiotics but that is all we can fight to get because we are fighting alone with our Lyme dr's. All because of a few ignornant money hungry greedy men. You kill people for money. You will be looking up not down when it is your time. Pure evil

Kenneth Poindexter I was originally diagnosed with Lyme disease in November of 2008, only after a year of daily migraine headaches, joint pain, muscle pain, brain fog, memory loss, sleep issues, blood pressure irregulation, fevers, chills, anxiety. Prior to 2007, I was relatively ok, with lots of inflamation that went undiagnosed for a total of 13 years.

No one ever even considered Lyme disease. I have had several Lyme tests done, all of which has come out showing something different. Sometimes I'm positive, sometimes I'm negative.

I have Ehrlichiosis and Bartonella too. Unfortunately, even with treatment, my Ehrlichiosis titers just go up, THATS RIGHT, UP.

I was treated for a year, made it to remission and then relapsed again in 2010. My symptoms have been exponentially worse than before.

If I had been diagnosed in 1994 when I originally started having symptoms, all of this could have been avoided.

SubLyme Contender im sorry...im going to have to laugh.... in your responses you are demanding respect in saying no foul language or calling names....but you wont respect us?we have to be nice and play pretty where you are concerned...but people are suffering and dying and watching their children suffer and mothers and fathers suffer.....siblings...grandmothers grandfathers.....and watch our life slip away along with our dreams...and not even given a chance to overcome this disease.....and you are demanding respect?....im sorry...you first faults is thinking you are Gods...and to sit on your thrones and tell us How to suffer?.....thats its all in our heads?...and dont care about your loved ones...they are crazy too?....and please dont make us laugh that u actually had a life to live?....US IDSA are increasing the surplus population.....sorry, you are just a casualty of war.....

Stephanie Vandagriff More evidence that Lyme is persistant.
http://www.plosone.org/article/info:doi/./journal.pone

Sonya Nelson What about this study?
http://www.plosone.org/article/info%Adoi%F.%Fjournal.pone.

PLoS ONE: Persistence of Borrelia burgdorferi in Rhesus Macaques following Antibiotic Treatment of D
www.plosone.org

PLoS ONE: an inclusive, peer-reviewed, open-access resource from the PUBLIC LIBR...

Mary Shaffer We should have a rally @ the IDSA.

Cari Ince dec. of 1990, we had our first child. i was the happiest i ever was in my life; so in love with my new daughter, so in love with my husband. we had such a bright future ahead of us. our daughter seemed to do everything early. at mos she was able to sit up and play with her hands free. she was starting to talk. (i read to her practically from birth.) she had a little board book with pictures of animals in it. her first word was "cat". she was very amused with our fluffy himalayan cat. quickly followed by "mama" then "dada" then followed by many more wordswhen she was just mos old, we took a trip to Nantucket Island. i was feeling so healthy and happy when we first arrived. then this itchy rash appeared; round, with a dark pink border and a dark spot in the center. i just wrote it off as a harmless insect bite.

Isaiah Goodwin So for 7 years I have suffered everyday, lost a job, watched my wife suffer for 6 years and now my daughter for 4 years from CHRONIC LYME DISEASE... We have learned so much about this disease that would love to debate this issue because all 2000+ people would win this debate. We have lived the pain, the depression, the feeling of wanting to crawl out of your own skin and it never goes away it's always there in one form or another. Lyme Disease takes away your personality and you longer enjoy life. It is basically putting people in jail while in severe pain and not helping them but still with bills and kids and responsibility. It's worse than jail and worse than death. There is no debate on if this is real or not real it's happened now to many people so before the entire world finds out you all did this for money you should change your guidelines and look for a cure to save lives. We have all lost enough time and money because of your small IDSA bio weapon cover up. The sad part is of course you guys know this is a bacteria man (scientist) changed into a form that will trick the human immune system to not come out on blood test, to attack our own bodies and to be very hard to treat. If you did any research on this or spoke to people, Lyme dr's and learned what I have you would know how many lives you killed, ruined and ripped apart. Imagine your innocent child in pain everyday missing out on their life.

Because of money for some greedy people. This is murder and your killing people slowly and it's torture and everyday is a struggle. We are all telling hundreds of people and contacting our politicians and media and soon there will be no running from the truth. There are studies you just choose not to count them. You pick the one study done between 2 people with lyme that wern't even on antibiotics that are used in most with lyme and that is your study for the guidelines. That is what makes me so mad. To know how many are walking around with pain everyday who don't know they are even sick makes me sick. So many who died and the cause of death was MS or heart block all because nobody found the lyme. It took me 10 Dr's before my wife diagnosed me from hundreds of hours of research and then got me to a LLMD testing positive for lyme, Bart and Babesia yet my Elisa and Western Blot in the lab was negative with my primary care. I had every symptom of lyme and the top dr's don't know it seems a little weird to me that they aren't made to play dumb. I know people are benefiting from this horrible disease Pharma Companies, FDA, CDC, IDSA and god knows who else. This is all about money and our lives ruined for it. It's time for someone to stand up and do the right thing and stop murderering people.

Jo Smith *Since you asked... Personally, I would like to see your organization disbanded. You keep persecuting doctors who try to help us, chronic Lyme sufferers. You are doing more harm than good. Please, go away. Preferably, before we die.*

Isaiah Goodwin also these studies above show proof of chronic lyme yet the way the bio weapon was made in world war 2 was for the human immune system not for the animal. Animals can handle this illness and be treated so much easier so whatever a test shows in a rat or any non human is going to be so much better than in humans. Since our immune system is fooled by it and so it attacks our own bodies this was designed by a human scientist to make this happen on humans and it is already known that most animals such as cows and horses have lyme disease approx 80% to 90% . They can tolerate it better than we can and I know this is well known by anyone who does any research into this disease. This is a corrupt hidden cover up and we are all going to stand together and make everyone know the truth. We deserve proper health care just like someone would want for their cancer or diabetes. Change the guidelines and make it right.

Sarah Jean Isaiah - I'm just curious how you explain the fact that the autopsy of the IceMan Remains showed the genetic footprint of Lyme disease in his DNA if this was created during WWII? I'm not attacking, just curious. I've dealt with Lyme, Babesia, and Bartonella myself.

Here's a link to the article by National Geographic: http://ngm.nationalgeographic.com/2011/11/iceman-autopsy/hall-text

"Perhaps most surprising, researchers found the genetic footprint of bacteria known as Borrelia burgdorferi in his DNA—making the Iceman the earliest known human infected by the bug that causes Lyme disease."

Kenneth Poindexter http://www.youtube.com/watch?v=eEE6aUjEHJY&feature=youtube_gdata_player

We won't be silensed anymore. We will be here until you act on your own mission statement.
Expand Preview

Kenneth Poindexter http://www.youtube.com/watch?v=vNtpty2WCo0&feature=youtube_gdata_player

Just in case you haven't seen the documentary or don't know the facts. The full feature is available on Netflix.

Jo Smith Since you asked... Personally, I would like to see your organization disbanded. You keep persecuting doctors who try to help us, chronic Lyme sufferers. You are doing more harm than good. Please, go away. Preferably, before we die.

Kenneth Poindexter I want one day without having to resort to morphine to control my pain. I want one day without a migraine headache. I want one day without forgetting what I was doing, I want one day to be cured of this hell the IDSA has placed me and those I love in.

Lynn Olson-Tuma What I want from the IDSA is to see more of your members embrace the fact Chronic Lyme Disease is exists and is seriously affecting millions of people around the world. I also like to see a review of the guidelines for diagnosing and treating Lyme Disease so that people can get the treatment they need to get well.

Donna Zukaitis Falcone Undisclosed Lyme Nearly Killed NC Cancer Researcher http://www.wral.com/lifestyles/healthteam/story/8331364/

Carl Tuttle The online petition against the IDSA member's Lyme disease study has gathered 315 signatures from across the US, Canada, Germany, UK, Ireland, Belgium, France, and the Netherlands. Please take a moment to read why doctors, nurses and Lyme patients are signing this petition.

There are now seven states which have passed legislation to protect clinicians who treat late stage Lyme with long term antibiotics (CT, RI, MA, MN, NY, NH, and TX with PA pending) and there are support groups in nearly every state with nineteen in Pennsylvania alone.

If the IDSA and CDC got it right with their "one size fits all" treatment approach for all stages of Lyme disease and faulty two tier test algorithm why then do we have this much legislation involving Lyme disease?

Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-lyme-disease

Carl Tuttle
Hudson, NH
Website:
http://home.comcast.net/~runagain/site/?%2Fhome%2F
January 14 at 9:01am · Like · 7

Andrea Marie-Greene Leuck I would like you to PLEASE CHANGE your guidelines and WORK with ILADS Doctors who are actually out there working with lyme patients and getting results.
January 14 at 9:40am · Like · 9

Phyllis Shaw It seems the IDSA is being proven wrong again. Poor dears. Can someone please pass them a wet towel so they can get the egg slop off their face- again?

On Friday the 13th- here is a new study providing more proof that spirochetes CAN survive after long-term antibiotic treatment.
Who'd thought that?

Embers ME, Barthold SW, Borda JT, Bowers L, Doyle L, et al. (2012) Persistence of Borrelia burgdorferi in Rhesus Macaques following Antibiotic Treatment of Disseminated Infection.

PLoS ONE 7(1): e29914.
doi:10.1371/journal.pone.0029914

"Our studies do however offer proof of the principle that intact spirochetes can persist in an incidental host comparable to humans, following antibiotic therapy. Additionally, our experiments uncover residual antigen associated with inflammatory foci."

Abstract

The persistence of symptoms in Lyme disease patients following antibiotic therapy, and their causes, continue to be a matter of intense controversy. The studies presented here explore antibiotic efficacy using nonhuman primates.

Rhesus macaques were infected with B. burgdorferi and a portion received aggressive antibiotic therapy 4–6 months later.

Multiple methods were utilized for detection of residual organisms, including the feeding of lab-reared ticks on monkeys (xenodiagnosis), culture, immunofluorescence and PCR.

Antibody responses to the B. burgdorferi-specific C6 diagnostic peptide were measured longitudinally and declined in all treated animals.

B. burgdorferi antigen, DNA and RNA were detected in the tissues of treated animals.

Finally, small numbers of intact spirochetes were recovered by xenodiagnosis from treated monkeys.

These results demonstrate that B. burgdorferi can withstand antibiotic treatment, administered post-dissemination, in a primate host.

Though B. burgdorferi is not known to possess resistance mechanisms and is susceptible to the standard antibiotics (doxycycline, ceftriaxone) in vitro, it appears to become tolerant post-dissemination in the primate host.

This finding raises important questions about the pathogenicity of antibiotic-tolerant persisters and whether or not they can contribute to symptoms post-treatment.

http://www.plosone.org/article/fetchArticle?articleURI=info%3Adoi%2F10.1371%2Fjournal.pone.0029914%22

Carol Gauthier Please study Lyme disease and its chronic form. Change the treatment guidelines to reflect the body of evidence many doctors have been accumulating while treating Chronic Lyme. I have the chronic form and find it very frustrating that IDSA has blinders on in regard to all the evidence that's been documented by the many doctors treating chronic Lyme. IDSA is treating Lyme disease patients like Fibromyalgia patients used to be treated - the doctors said there was no such thing, therefore, it's all in the patients head! PLEASE reconsider the guidelines.

Jean Hemond Your answers on our comments about your Lyme disease guide lines are an insult to public, patients and caring MDs intelligence and honesty. It appears much easier for IDSA to barricade behind self proclaimed expertise denying all other sources of studies and data that for most sustain chronic Lyme.

Isaiah Goodwin *. . . . .The sad part is of course you guys know this is a bacteria man (scientist) changed into a form that will trick the human immune system to not come out on blood test, to attack our own bodies and to be very hard to treat. If you did any research on this or spoke to people, Lyme dr's and learned what I have you would know how many lives you killed, ruined and ripped apart. Imagine your innocent child in pain everyday missing out on their life.*

Because of money for some greedy people. This is murder and your killing people slowly and it's torture and everyday is a struggle. We are all telling hundreds of people and contacting our politicians and media and soon there will be no running from the truth . . . . .

Wrblr Fvtwlv

http://www.plosone.org/article/fetchArticle?articleYOURI=info%3Adoi%2F10.1371%2Fjoyournal.pone.0029914

Karla Williams
http://m.discovermagazine.com/2012/jan-feb/90
Scientific proof Chronic Lyme disease Does Exist

Gretchen Ahlers When considering the issue of stewardship, it is necessary to have an understanding of what one is actually a steward of. Is it merely tending a budget in terms of judicious and fair distribution of monies entrusted? Well, yes, partly, but, does stewardship also encompass much more? Does it involve a judicious use of the "clout" an individual or organization of individuals have?

For example, let's say I am a winsome and attractive person who hangs around the school yard smoking cigarettes? The question is, am I stewarding the influence I may have upon young kids who might decide I am to be their role model? The answer is obvious. I have not judiciously stewarded my personality and attributes in a way that promotes the success of others, in fact, I have actually created a situation of leading many malleable minds and bodies to detriment. In the same way, to have the power or "clout" to define and shape policies, guidelines and treatment protocols, while refusing further investigation of provocative evidence and testimonials which contravene current standards is what would by this reasoning, be categorized as a poor steward in deed.

Kaethe Mitchell We have two kids whose lives have been completely demolished by Lyme and confections due to a lack of adequate testing, and this substandard resting is blessed by IDSA. If I walked into my doctor's office today and described every commonly seen symptom of Lyme disease, my doctor would look up the IDSA guidelines and order a "Lyme test", i.e. the ELISA. If that were negative, as is the case in up to 50% of cases, I would go on to develop a late-stage deeply entrenched condition where the bacteria moved into my brain and spinal chord, joints, GI tract, pretty much every system of my body, as happened to my kids. The same thing would happen to my neighbor down the street, the person in the next town, etc. until thousands of people were extremely ill. This is, in fact, happening right now. This is all because of antiquated IDSA guidelines. What's it going to take to change them this year, in 2012? I'm getting the clue there are thousands responding to this question who know that a change in the IDSA guidelines is long overdue. What's it going to take, IDSA?

Debby Matthews All I can say at this point is that the IDSA is a joke and a bunch of cowards who cannot address any of these questions and concerns from the people that they have asked "What would you like to see from your society in the coming year?" Nearly 3000 people have commented here and nothing from the IDSA in response! Seriously... You are a waste of time & energy and have done nothing but delete and block people with a real disabling disease and that just want some answers....real answers to save their lives and the lives of loved ones...Heartless Cowards and Useless!!!!!
I have NO respect for the IDSA what so ever and am personally not going to waste any more of my time or energy or any breath I have left beating this dead horse.. People who suffer from this "DEADLY" disease WILL find the help that they need from real doctors who have compassion and the KNOWLEDGE of LYME DISEASE to help them...Yes it is difficult...But so is dealing with the IDSA who has NO compassion or knowledge apparently of the REAL suffering and struggles of real people with a real disease! Shame On All Of You! You WILL answer to a higher power and You will lose! So Delete this post and block me...I don't care! You're USELESS! We are all on our own in this life and we will find a way to save our lives...Without your "help"....IDIOTS! I'm Done with you stooges!......

Kim DeSantis Goodwin Sarah jean Lyme started in Europe and the iceman having Lyme. In world war 2 the nazi Traub is the cause of Lyme. Here is some reading on this. It was a simple bacteria changed into a bio weapon. Haven't you heart of Plum Island and Lyme disease?
http://www.rense.com/general67/plumislandLyme.htm
everyone should read this.

Plum Island, Lyme Disease And Operation Paperclip - A Deadly Triangle
www.rense.com

Linda Slocum I would like to see the IDSA taking a realistic look at the treatment of Lyme disease, rather than the usual whitewash created by the current panel who has been convicted of conflict of interest in this matter. Many studies have come out proving that Lyme is absolutely not cured by 10 days of Doxycycline, and in reality takes much longer to treat than even 30 days on an IV medication such as Rocephin in many cases. It would be great to see treatments based on actual medical research and patient studies rather than the outdated opinions of the IDSA board.

Linda Slocum *I would like to see the IDSA taking a realistic look at the treatment of Lyme disease, rather than the usual whitewash created by the current panel who has been convicted of conflict of interest in this matter. Many studies have come out proving that Lyme is absolutely not cured by 10 days of Doxycycline, and in reality takes much longer to treat than even 30 days on an IV medication such as Rocephin in many cases. It would be great to see treatments based on actual medical research and patient studies rather than the outdated opinions of the IDSA board.*

Kim DeSantis Goodwin Remember everyone can leave comments without liking their page I know nobody who left a comment likes the IDSA. Please unlike the page.

Kenneth Poindexter It seems that the IDSA has forgotten their own mission statement. Here it is, " IDSA's purpose is to improve the health of individuals, communities, and society by promoting excellence in patient care, education, research, public health, and prevention relating to infectious diseases." They have utterly failed this mission where it comes to Lyme disease and its confections.

Melissa Jason at least we know that they are reading our posts considering they keep deleting them....

Sarah Jean Kim my response about the Iceman mummy was due to another person's comment eluding to the fact that Lyme originated from Plum Island experimentation. Maybe I read/understood it wrong. It seemed to me that this person was claiming that Lyme started with Plum Island, but there is hard evidence that Lyme existed 5,300+ years ago.

I've heard of and read about Plum Island, but usually the people talking about it are fanatical conspiracy theorists (I know not all of them are). I very much believe the Plum Island theory is possible.

Many of the Plum Island claims are ideas/theory, without adequate hard evidence, although a lot of it is very convincing (and I very much understand that the government is not going to admit to bio-warfare and mistakes it has made, especially with Lyme experimentation).

The people who host the information on the link you referred me to even say, "We choose not to censor skewed logic and uncomfortable rhetoric...We present multiple facts, perspectives, viewpoints, opinions, analyses, and information."

It is up to us to consider all sides, just as we are asking the IDSA to do. It's possible that there is a modified Lyme bacterium created by experimentation on Plum Island, and it's possible that the original Lyme bacteria and modified bacteria combined/evolved to create new varieties... It's possible that the government has helped to accelerate a disease that was already going to overtake people anyway. It's also possible that there are no genetically modified Lyme bacteria, and it's just resourceful enough to evolve into variations that guarantee its survival. Anything is possible...

Paula Gallo A Rife machine in every community to the specification of Royal Rife will cure a lot of things like cancer and TB. IT ALSO CURES LYME. All in the name of the Big Pharma chemicals you support, Rife was shut down
http://www.youtube.com/watch?v=2yASljAG5Zo&featyoure=related

Kenneth Poindexter Was Lyme created at Plum Island, probably not. Many people do believe that it was experimented with and ultimately led to the outbreak in Lyme Conn. I don't know the truth, I do know that Lyme went for millions of years without so clearly infecting so many.

Joan Rome Ballou Lyme Disease Guidelines changed to reflect the TRUTH. My daughter has suffered for 38 years from Chronic Lyme. DO SOMETHING NOW to help all those who are suffering because of your outdated self-serving guidelines.

Maureen Tanguay Honesty is a beginning........... Lyme Disease Is Spread By Mites, Spiders, Mosquitoes, Fleas. It Is Also Spread Via ALL Body Fluids

By Patricia Doyle, PhD
8-3-11

Hello Jeff - We said this many years ago on your program and here it is. Lyme disease can be transmitted via contact with body fluids, such as urine, tears, semen,

We discussed the contaminated blood spread a couple of months ago. Lyme was transmitted to people who had blood transfusions. Also, the deer tick is not the only means of spread, fellow arachnid the spider, biting flies, fleas and mites are just some of the culprits that spread Lyme.

So, reducing deer populations by slaughtering these magnificent animals will do nothing to end Lyme Disease spread. Even adding to the slaughter all birds and deer mice and small mammals would not help stop Lyme. That biowar genie has been out of the bottle for too many generations, thanks to our "Plum" friends.

Patty Treating Lyme Disease Naturally
Posted by Delia Quigley Jul 30, 2011

Filed under: Alternative Therapies, Blogs, Diet & Nutrition, General Health, Health & Wellness, Natural Remedies, Rejuvenate your Body with Delia Quigley, antibiotics, Healing Lyme, Lyme disease, spirochete

It may begin with flu like symptoms, headache, chills, and body pains. That is, if you're lucky enough to know you've been bitten by an infected tick. However, some people won't know, because Lyme disease can also be transmitted by contact with body fluids such as urine, tears, semen, contaminated blood and breast milk. Plus, it is not only ticks that now carry the Lyme spirochete, but also mites, spiders, mosquitoes, fleas and biting flies.

Antibiotics whether administered in a one month protocol or taken intravenously for several years, has been the only way allopathic medicine has treated Lyme disease. For many this form of treatment has successfully eliminated the debilitating symptoms, while for others antibiotics have only offered short-term relief. According to Stephen Harrod Buhner, author of Healing Lyme, 80 percent of blood tests performed to detect the presence of Lyme come back negative. This, he claims, is due to the spirochete's ability to hide inside cells and body tissues rather than body fluids and blood, to quickly arrange its gene structure in order to hide from antibiotics and fit into the host's body, all while avoiding their immune system. In addition to bacteria, Lyme ticks can also transmit Babesia species, a small protozoan, which only complicates the disease further. There are a number of natural protocols, using herbs, diet and energy treatments that have helped many people suffering from Lyme disease. Some are listed here not as a medical cure, but as alternative treatments to help alleviate Lyme symptoms. It is difficult to say what will work for one person and not for another, so it is recommended you work with an experienced health practitioner to determine the right supplements for you to take. It is important to remember that herbs are medicine and should be treated with respect as to dosage and use over time. (1 of 4 parts)

http://www.care2.com/greenliving/treating-Lymes-disease-natyourally.html

Patricia A. Doyle DVM, PhD Bus Admin, Tropical Agricultural Economics Univ of West Indies
Please visit my "Emerging Diseases" message board at:
http://www.emergingdisease.org/phpbb/index.php
Also my new website: http://drpdoyle.tripod.com/ Zhan le Devlesa tai sastimasa Go with God and in Good Health

Benjamin Franklin said, "They that can give up essential liberty to obtain a little temporary safety deserve neither liberty nor safety."

MainPage
http://www.rense.com/
This Site Served by TheHostPros
Treating Lyme Disease Naturally
www.care2.com
It may begin with flu like symptoms, headache, chills, and body pains. That is, if you're lucky enough to know you've been bitten by an infected tick. However, some people won't know, because Lyme disease can also be transmitted by contact with body fluids such as urine, tears, semen and contaminated blood.

Allie Wetzel More funding for Lyme research! I was misdiagnosed with MS and Lupus before finally being [correctly] diagnosed with Lyme disease. We need better diagnostics AND better treatment plans for Lyme Disease.

In 2010 I competed in the Collegiate National Triathlon. I had hoped to place in the top, but barely finished. The chronic fatigue I had been experiencing since 2006 was now debilitating. My 4.0 at UF was damaged by classes I barely passed as most days I could not drag myself out of bed. I was hospitalized after a short track workout and found myself unable to do anything more active than walking my dogs. I was forced to cancel my 2010 Florida Ironman Entry and watch my bikes collect dust. I sought medical opinions and was misdiagnosed with Lupus and MS diseases I thought would end not only my athletic career, but also my life. In May 2010, Dr. Kim Kaye in Gainesville Florida gave me the first glimmer of hope- she told "You have Lyme Disease and I can fix you". She was right, and after 9 months on Doxycycline, Zofran, and Tramadol I was cleared to train again. I am now coached by Tina Pic and am entered in the 2012 Florida Ironman. November 3rd 2012, exactly 2 years after being diagnosed with Lyme, I will line up on the beach, shaking and scared, and I will become an Ironman. I am still plagued by autoimmune flares and residual symptoms, but this is a fight I will never lose.

Please find ways to increase all aspects of research on this disease. Starting a cycling or triathlon team similar to Team Type 1 would be a good start... I would help in any way I could.

Hope McCoy This is just plain scary! Recently diagnosed!

Karla Williams You are right on Maureen...tell it!

Karla Williams Hope I was Dx'd in 2005, that was scary. There was no information, no real support. It has spread like wild fire and is coming to critical mass. We have blazed the trail you will walk, are fighting the battles that you will not have too. However, educate yourself well, and prepare. Message me on my facebook for more information. ISDA are liars and are paid and kept by big pharma, insurance industry and special interest. That special interest is NOT YOU!

Stephanie Martinez I would like the Lyme guidelines to be corrected...I have been n pain for almost three yrs...told I have ms etc and fome to find out its Lyme....I could been having treatment if your guidelines were correct...

Stephanie Michelle Kealy "More than half of the current recommendations of the IDSA are based on level III evidence only. Until more data from well-designed controlled clinical trials become available, physicians should remain cautious when using current

guidelines as the sole source guiding patient care decisions."
http://archinte.ama-assn.org/cgi/content/abstract/171/1/18?etoc
IDSA: “Our goal is to ensure that patients are given treatment that is safe, effective and supported by scientific evidence."
http://www.idsociety.org/Lyme_Review_Panel_News_Release/

Stephanie Michelle Kealy the above links posted by me were posted by a woman a few days ago... her comment was deleted and she was banned from future posting on this page. If you want people to know the truth, copy and paste. Can IDSA block everyone?

Isaiah Goodwin Sarah Jean the other person was me and you are talking to my wife and I was the other person. Lyme Dr’s do believe that Lyme started long ago in Europe and then it was man made changed into this sick form. Are you someone who has Lyme or someone writing on behalf of the IDSA. Confused with this and its off the point of people dying from guidelines. Even if the small chance this was just a bacteria that formed into this complex form were true at the end of the day we are all sick because of the IDSA .

Paula Gallo This cant be ignored any longer. Fess up. You are either with the people or not. Make a decision. http://vimeo.com/34538925

Sherri Anderson Because of IDSA Guidelines, my daughter has been misdiagnosed for 3 years. Because of your guidelines, we were told her blood tests were negative and only in the past month have learned her Western Blots were always reactive to B.Burgdorferi SPECIFIC antibodies. Because of your guidelines, her illness was never identified or treated but allowed to progress and she now suffers from NEUROBORRELIOSIS, identified NOT by a LLMD but by a "Lyme aware" neurologist. Because of your guidelines, she has developed an autonomic disorder as a result of long term Lyme infection. Because of your guidelines, she is no longer an active teenage athlete and honor student, but must rest in quiet much of the day due to her painful symptoms, cannot sleep at night, and can no longer attend school. IT IS TIME TO CONSIDER ALL EVIDENCE AND HELP PEOPLE WHO ARE SICK. THE GUIDELINES NEED REVISING.

Daniel Anderson Perhaps its time to change the guidelines when 2,250 people would ask you to... but that would make way to much sense wouldn't it? What a joke of an organization.

Linda Slocum I would like to see proper testing for Lyme, instead of using the highly limited criteria that was originally designed for surveillance purposes only. Ignoring the majority of the bands significant for Lyme is just plain criminal, as it appears to be a deliberate attempt to reduce the reportable incidences of Lyme disease, and thus gives the insurance companies carte blanche to deny that Lyme exists.

Sara Schultz I'd like the IDSA to explain to me why ticks infected with Lyme disease in Canada only bite dogs .... and not people?

Robin Krop To talk your walk. When push comes to shove, you call ILADS LLMDs. For example, when Pres ‘ Bush got Lyme, you called two ILADS LLMDs to ask what to do.

Joan Rome Ballou My daughter was infected by a tick bite on SHELTER ISLAND, NY. Around 1979-80. This is where Burgdorfer obtained the ticks he used for his initial research on "Lyme Disease" before it even had a name. She has been sick ever since. And you think Chronic Lyme doesn't exist?

Leslie Feinberg "Casualty of an undeclared war" series
Leslie Feinberg's personal research notes
on the medical politics driving the Lyme wars.

http://www.transgenderwarrior.org/Lymeseries.html

Deborah Via Dixon OK, idly your picking on me by deleting my posts. I have said nothing wrong to have you do this. By this post I will let you know that I WILL NOT GO AWAY! The group of so call people (as I really don't know how they can be called people as they apparently have no souls) needs to be banished from the "society" as they clearly cannot see that their decisions are wrong! How many people do you need to be heard from? How many people must suffer? How many people must lose their jobs, their homes, their savings, their ability to care for themselves and others? How many family members must watch daily as their loved one suffer? All because of one panel of self imposed GODS? Shame on you

Michelle Bly Ladzenski Recognize that, for whatever reason, Lyme doesn't "go away" the first time around in some patients. After recognizing that, you have to be willing to treat patients with persisting symptoms.

Melissa Griegel ISDA: You asked, we answered. Now are you going to listen and actually do something about it?

Melissa Rascio Make sure to sign this petition as well...967 signatures so far...urge your family members to sign.
http://www.change.org/petitions/revise-idsa-guidelines-for-Lyme-disease

Kathleen O'Connell A quote by Martin Luther King. "Never, never be afraid to do what's right, especially if the well-being of a person or animal is at stake. Society's punishments are small compared to the wounds we inflict on our soul when we look the other way."........ I couldn't help but think of the IDSA after reading that quote. They have my life in their hands right now. By omission and looking the other way they are doing harm and some of us will succumb to Lyme Disease before THEY do what's right.

SubLyme Contender ALL of us Lymies are very aware that you IDSA did not infect us with this disease....and we are not blaming you for us being sick......But its time to open the guidelines to the point that ALL TREATMENTS can be available to all Lymies according to the patients and the docs who treat us....so therefore...Please know that we know you didn’t infect us...BUT GET THE HELL OUT OF THE WAY SO WE CAN DEFEAT THIS THING...IM TIRED OF BEING TOLD HOW I FEEL BY SOMEONE WHO DON’T EVEN LIVE IN THE SAME STATE AS ME OR SAT DOWN AND ATE A MEAL WITH ME.....SO THEREFORE IF YOU ARE NOT GOING TO HELP US....THEN MOVE AND LET US TRUE FIGHTERS DO SOMETHING WITH THESE INFECTIONS.....US LYMIES ARE PROACTIVE...UNLIKE YOU ALL

Hannah Hollingsworth *I had to drop out of school and take a leave of absence from work because I can no longer understand sentences, forget about the fact that I'm operating with moderate pain in my knees, wrists, neck, and back, and constant headaches.*

Kathryn Richards so they have proven chronic Lyme in monkeys!!! When will the IDSA catch up?
http://www.prohealth.com/library/showarticle.cfm?libid=16759#.TxRikpXcKUc.facebook

Aggressive antibiotic therapy could not kill all spirochetes in monkeys with disseminated Lyme disease
www.prohealth.com
In monkeys treated with antibiotics after 6-8 months of infection, enough spiroc.....See More

Kathryn Richards and yes, in fact, did call local vets to see if they would treat humans and ordered doxy from an online vet supply store. Pretty pathetic to think this is America. Learned to run my own IV on youtube finally. This is beyond repulsive to think this is America.

Lori Kaciak Newsome chronic Lyme disease... is slowly killing me. It has its grip on my life and is slowly but surely squeezing every ounce of my energy to pulp! I can barely keep my eyes open trying to type this. Please help us......

Angel Williams Spell well my argument is you spend all this money trying to prove us wrong and telling us research doesn’t support what us Lymies say....but we are the ones on the front line. If you want to save money and healthcare, just listen to us the ones who are suffering....if you would just listen...you could save lives...money etc....When I’m on my death bed….. I want to know that I made my mark on this world in a positive way...not that I mutilated innocent lives just to try and prove someone wrong...come on....do something good with your life....you don’t want to be known and the modern day Hitler do u?....Its not hard.... just take a deep breath...admit where you are wrong...and save some lives...just think of all the prestige... YOU saved thousands of lives....I would much rather be known for that if I were in your position

Danielle Michael Handy I would like to see recognition of the fact that 6-8 weeks of antibiotic therapy is not enough treatment for many people and if symptoms still exist after that time I would like to see research as to why and what is causing it and how can it be treated. I would like to see infectious disease doctors and primary care doctors more educated in the many symptoms a tick bite can be. I would also like to see more education and recognition on all the other diseases a tick bite can transmit.

Sarah Jean Isaiah, it's all good. I think I just misunderstood your previous post. Don't worry, I am NOT writing on behalf of the IDSA. I dealt with Lyme, Babesia, and Bartonella for many years.

Kaethe Mitchell Hooray! Just received my copy of Dr. Burton A. Waisbren Sr.'s "Treatment of Chronic Lyme Disease - Fifty-One Case Reports and Essays in Their Regard". http://www.amazon.com/Treatment-Chronic-Lyme-Disease-Fifty-One/dp/0982513887/ref=sr_1_2?s=books&ie=UTF8&qid=1326765209&sr=1-2

Deborah Via Dixon http://whatisLyme.com/rest-in-peace/ *food for thought IDSA*

Jennifer Christie I would like to see some tests and treatment for Babesia. Over 30 deaths from blood transfusions and no one has any answers. This is a vector-borne illness and people are dying from it. Red Cross has no idea what to do. I spoke with Dr. Lieby himself and he confirmed my fears.

Stephanie Vandagriff Were all on the same side Isaiah and Sarah.

Jennifer Schierholt For starters, we need doctors brave and wise enough to make reasonable clinical diagnoses of Lyme based on presenting evidence. Everyone knows - even your own experts admit - that currently available tests for Lyme are unreliable, so they should hardly be considered the gold standard for diagnosis. 48 hours after returning from a trip in the backcountry, my husband walked into the ER with textbook perfect symptoms of Lyme - EM rash, fever, joint pain, etc. He was told he couldn't possibly have Lyme because "we don't have Lyme in Southern California." Bounced from specialist to specialist for two years, he's been told he might have: allergies, rheumatoid arthritis, delayed pressure Urticaria, Trigeminal Neuralgia, Chronic Fatigue, Dengue fever... the list goes on. He finally has been diagnosed with Lyme, but now he has swelling of the brain, spinal cord and heart; vision and hearing loss; Papilledema; extreme bone pain; extreme chest pain; shortness of breath and cognitive difficulties. All because doctors ignored what they saw in front of them and made wild speculations instead. My husband has lost his health, his career - and possibly his life - because not one doctor was willing to make the most reasonable diagnosis based on the physical evidence. This didn't have to happen. It should NOT have happened.

Holly Kitchin Roesing Lyme Disease RECOGNITION! Need a Lyme Doctor in South Carolina. Nobody believes in it down here!!

Steve Hardister Lyme, why did it take a year and thousands of dollars, and 4 doctors?

Steve Hardister Finally getting better, WITH NO HELP from the main stream doctors!!!!!

Melissa Jason I say we take this protest even bigger. Why don't we question Bush on his treatment he received for Lyme Disease? He claims that his Lyme treatment is classified but later gave full details for the procedure of his Colon surgery...hmmmmm.......

Deborah Via Dixon http://discovermagazine.com/2012/jan-feb/90 check this out IDSA!

Hannah Hollingsworth Here's some scientific proof of persistence of Borellia after antibiotic treatment. It's not all in our heads. http://www.plosone.org/article/fetchArticle?articleYOURI=info%3Adoi%2F10.1371%2Fjoyournal.pone.0029914

Hannah Hollingsworth I had to drop out of school and take a leave of absence from work because I can no longer understand sentences, forget about the fact that I'm operating with moderate pain in my knees, wrists, neck, and back, and constant headaches.

Brian Carissa Dietz My husband has Lyme disease. He had a heart attack in August and while I am grateful that the University hospital saved his life, they refused his Lyme treatment during his stay and interrogated him daily concerning Lyme Disease. The Infectious Disease Dr. that follows your guidelines would not give him his antibiotics and his fever went up and he was having crushing chest pain and could not breathe- his symptoms were ignored and he was discharged only to be flown to another hospital a few days later where they found blood clots in his lungs. I also have Lyme Disease/Mycoplasma. It presents as Multiple Sclerosis that started when I was a child and diagnosed as the classic 'growing pains'.

I have suffered with this my whole life and passed it on to my children. You can not imagine the pain, not only the physical pain but the heart wrenching pain watching my children and husband suffer. Also my daughter, then 3 year old was bitten by 4 ticks in a 2 week period at her daycare. Her Pediatrician refused to treat her based on your guidelines and unreliable testing. Within weeks she was experiencing daily headaches, fevers, swollen glands, sore throat, back pain, worsening of joint pain and what she called sprinkling feeling in her legs and we noticed a drastic change in her personality. The scientific proof is there. I am asking you to please revise your guidelines. So many people are suffering from this disease.

Gretchen Ahlers This is truly heartrending to read, especially the part about Lyme patients not getting safe and individualized care in hospital settings. Where is the moral leadership in this issue? Practitioners who have dealt with hundreds of patients with Lyme know that Lyme causes the blood to get "sludgy" . Strokes and other blood clotting events are associated with Lyme, if not research confirmed. The surgeon who places the IV port in Lyme patients knows this and acts judiciously. We again find the glaring question of why would those doctors who "own" the realm of infectious disease not be interested in examining a reality that their peers are well aware of, and handle with caution? If one doesn't know, one conscientiously consults with someone who does. But what happens when the phone is dialed for batman and joker pops up?

Cecelia Cece Price Jones I guess I was deleted! Well, tell me again how the efx of Lyme could be all in my head when my hand became paralyzed without evidence of a stroke? & major blasts of Rocephin got my hand moving again???

Layoura Galvan @sara jean- how did you get better?

Lori Ditzler Hagarman I wonder when one of you or someone in your own families will suffer from this disease? No one is immune and the numbers are growing!!!!

Kathryn Ely I would like to see a change in the IDSA guidelines for Lyme Disease. I would specifically like to see a balanced panel free of special interests review actual medical facts that have been published in various journals of medicine/pubmed, listen to patients symptoms and THEN draft a new set of guidelines.

You may or may not be aware of how many companies/organizations use your guidelines like they were written by god himself. The Social Security Administration is one example. I am unable to walk without the aid of a walker and even then can only go distances of 100 feet. I cannot sit, stand or lay in one position for more than 20 minutes. I have lost the use of fine motor skills, experience halted speech patterns, suffer from seizures daily, experience consistent pain on a level 8 out of 10 and can hardly bathe much less work. This is not "the aches and pains of everyday living". I am clearly disabled, but thanks to your faulty guidelines I have been denied SSDI/SSI twice and am now waiting for a hearing with a judge.

Meredith Lodge I would like to see a better test for Lyme covered by insurance. I like testing for other tick born diseases to be covered as well. Though I tested positive CDC Lyme in 2009, no doctor ran a test for Erlichiosis until Jan 2012. Tested positive. IDSA, I think if you and ILADS could meet together you are all so smart you could do great things for the individuals who need you, the Americans, the. Population of the A in IDSA

Becky Dietsche I have known numerous people who have been misdiagnosed with other illnesses, including myself, when they in fact have Lyme's Disease. Please change guidelines and help people find the answers they are looking for. I was lead to believe I had restless legs syndrome for two years before having an exacerbation and others symptoms come on. There are so many co-infections that accompany Lyme's Disease as well. Countless dollars are spent going from doctor to doctor for answers, more screening should be done and covered initially so that time, money and heartache can be averted. Thank you.

Susan Campbell Chris Finkle http://www.patient-experience.com/index.php/ccsvi-research-and-success-stories-multiple-sclerosis-and-Lyme-disease/

Melissa Dempsey The research about chronic Lyme yields conflicting results. When that happens, its time to listen to the patients. So here we are. Maybe its time to drop the insurance company politics and start listening. By the way, I love it when your doctors state things about the "antibiotic seeking behavior of the Lyme patients." In case you've never been sick, taking antibiotics are not a joyful experience. The only reason to seek them is if you have an ongoing infection. Time to start thinking outside of your little medical boxes.

Eran Nils Redick Government caused this Lyme outbreak, it escaped from Plumb Island bio-weapon... whoopsie. They are hoping we all just shut up and die!

Carl Tuttle Please take a moment to read the following letter addressed to the New Hampshire Department of Health and Human Services.
Jan 21, 2012

Deputy State Epidemiologist
Division of Public Health Services
Department of Health and Human Services
29 Hazen Drive
Concord, New Hampshire 03301

Dear Dr Dionne-Odom,

Eight years ago per the attached study two Huston Texas physicians tested their chronically ill patients for Lyme disease via CDC Western blot criteria finding all patients positive for the infection in a state where the prevalence of Lyme infected ticks is only about 1-2%
Excerpts from that study:
http://home.comcast.net/~runagain/LymeDiseasepandemic.pdf

“We recognized a striking similarity in symptoms and signs of test-positive individuals to other untested patients of yours. No history of bull’s-eye rash or illness following tick bite was reported by these patients.”

Elaine Facteau Walker *This is my second comment... my first was about lack of treatment and acknowledgement of this disease and the situations that people are facing. This time I would like to say "thank you" for posting your question and appearing to show interest in what people think/want, but I would also like to ask you, the IDSA for a reply to all of our comments.*

“There are two distinct but connected forms of human B. Burgdoferi infection. The yet-unrecognized form appears to have a broader clinical presentation, wider geographic distribution and vastly greater prevalence”

The CDC defines “Lyme disease” exclusively as a Zoonotic illness. Congenital and gestational transfer cases have been disregarded for reasons not evident to us.

“Patients fall outside the Lyme disease inclusion criteria. Ill patients presenting with disseminated symptoms without meeting defined Lyme Disease endemicity criteria are also at serious risk of not being considered BBSL infected.”
“The immune reaction of infected patients not meeting the Lyme disease criteria have fallen outside rigorous scrutiny.”

“Our clinical experience strongly suggests that predictable, possibly inevitable Lyme disease transfer between sexually active couples occurs. The preponderance of infected spouses we have tested to date also exhibit positive serology or PCR for BBSL presence.”

“Substantial data support the probability that human BBSL infection can persist indefinitely.”
“BBSL presence in human, other vertebrate reservoirs or both have been reported from over thirty countries on six continents and several islands. The Zoonotic model was, and remains incomplete, and includes only a portion of all B. Burgdorferi infected humans.”

“The data suggest there may exist a much larger unrecognized pool of BBSL-infected individuals sustained by persistent intra-human transfer that we provisionally call “Epidemic Borreliosis” Treatment modalities and schedules to eradicate B. Burgdorferi from all patients regardless of infection route or duration must be created. If our experience holds, this will be a difficult task and will require serious and rapid commitment from all nations.”

The current CDC limited and narrow Lyme disease case definition has not only caused much confusion within the medical community but has given our local health departments and insurance companies the license to ignore anything that doesn’t fit “into the box” further delaying the recognition of this epidemic.

In the town of Litchfield New Hampshire 77% of the deer ticks have tested positive for Lyme disease. (See attached tick study)
http://home.comcast.net/~runagain/NH%20Tick%20Study.doc
We are seeing entire families devastated by Lyme disease similar to what is described in the Texas study published eight years ago but on a grand scale and yet we continue to witness a denial of this epidemic.

You have to wonder; Is this intentional and do those in control actually know the extent of this epidemic? Look at all the Lyme legislation across the country. In addition to tens of thousands of patients, legislators and clinicians all want answers to why this health disaster has been allowed to spiral out of control.

Sincerely,

Carl Tuttle
33 David Dr
Hudson, NH 03051
(603) 479-4927
Website: New Hampshire Lyme Misdiagnosis

Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-Lyme-disease

Sonya Lawler To Sharrie Anderson - where is this Lyme aware neurologist? I'm sure can't find one in upstate NY!

Jill Kuschel It isn't just bad guidelines, it is your (IDSA) complete ignorance and lack of willingness to learn something new. You ARE criminals.

Lisa Hilton We lost another Lyme friend last night. Debbie Bodden, rest in peace...I wish you would recognize what this disease is doing to people and families.

Carmen Linderman I have lost 10 years of my life due to Lyme, I was told that I had MS and they were wrong. The past 3months I have been trying to get it back. I understand now it will take a very long time and money! If the physicians are educated to look for something they will, if not, they will not and it's like it does not exist. Just think of how many people suffer and have lost their lives due to ignorance! I can take my dog to the vet with a tick and it would get removed, tested and the dog would get treated just in case. If I go to the physician with a tick it would get removed, thrown in the garbage, then I get ignored if I say Lyme, something is very wrong! Why are animals more important than people, do vets care more than physicians? Please change the guidelines so at least we have a chance. No one can repair the damage to a family of a person who has Lyme.

Carmen Linderman And don't even get me started on the testing for Lyme!

Mary Shaffer Carmen, I would like the IDSA to understand our struggles, in getting treatment, in order for us to (hopefully) getting our life back! We have to seek out and find a Doctor that knows and understands this complex disease! We have to find a way to travel many miles and miles to get to this Doctor (some people have to drive hundreds of miles and cross state lines), then even those of us that have insurance have to pay out of our very own pockets for treatments! ALL because of the IDSA guidelines!

Melissa Jason IN YOYOUR FACE IDSA! http://www.icontact-archive.com/FBkbi1IUxiGEZy8CZmrP82C78eFGZehv?w=2. We are taking you down :)

Eran Nils Redick Am I crazy for thinking I might have Lyme or is Lyme making me crazy and not making me seek the help I might need?

Sonnen Schein Time to change the guidelines!

Sonnen Schein The number of infected people is rising. We won't give up until you recognize your mistakes!

Kenneth Poindexter IDSA, what do we want? This is what I want. I want chronic Lyme disease to be recognized and adequate treatment guidelines published that respond to the facts of the disease,

Kenneth Poindexter I want to live one day without pain, brain fog, fatigue, headaches, Raynauds Syndrome, chills, fevers, hallucinations, ringing in my ears, numbness in my hands, my feet. IDSA I want to live. I want the last 18 years of my life over so that I can enjoy my children who I have lost out on many of the joys of parenthood because of a disease that could gave been cured early on.

Kenneth Poindexter I don't care why this has happened. I don't even care that some of your review board has conflicts of interest and shouldn't have been on the review board to begin with. I don't want a public admission of wrong doing. I don't want to sue you, I don't want you to be bitten by a tick and suffer the daily pain and agony that I have. All I want is to be treated for the disease I have and not have to fight for my insurance company to cover a treatment that I and my doctors know will get me to remission. Yes, I said remission. I would be happy with that. I know a cure may never come.

Mary Shaffer IDSA, all we are asking for is to be able to get our quality of life back!!! The IDSA 'non-response' shows NO compassion, NO understanding , NO glimmers of caring about people that have this disease. A disease that we acquired, simply due to the fact that we were bitten by a tick! IDSA, crawl out from hiding under your rocks and give us a response!!! Don’t you hear our pleas for help!

Maryann Wall Tworek Who in the IDSA will have the courage to question the dogma and stop dismissing everyone who disagrees with you as a crazy or a quack? Don't you know you set the tone? As you show contempt toward sick patients, so do most other doctors, including those in other countries. PLEASE listen to the patients and doctors who are saying that Lyme is so much more varied and common than you suggest it is. Even separately from the disagreement over treatment, doctor education about the disease is abysmal, resulting in ongoing misery of infected patients. I had 16 months of decline and new symptoms incl. 2 ER visits and a 3 day hospital stay. I'd been essentially disabled for 6 months by that point. I was only diagnosed after I went out of network to a Lyme practitioner who confirmed what I already knew - that I have neurological Lyme. There's no excuse for this situation in America!

Bill Klavonski *This was a complete waste of time. They [IDSA] posted this by mistake and are now ignoring it; they are just waiting for it to fade away. I sent the story and link to every major news outlet, and not one of them responded. Perhaps if more of us had done that instead of expecting the IDSA to have compassion we would have gotten somewhere. We're all just talking to ourselves people.*

Elaine Facteau Walker This is my second comment... my first was about lack of treatment and acknowledgement of this disease and the situations that people are facing. This time I would like to say "thank you" for posting your question and appearing to show interest in what people think/want, but I would also like to ask you, the IDSA for a reply to all of our comments.

Bill Klavonski This was a complete waste of time. They posted this by mistake and are now ignoring it; they are just waiting for it to fade away. I sent the story and link to every major news outlet, and not one of them responded. Perhaps if more of us had done that instead of expecting the IDSA to have compassion we would have gotten somewhere. We're all just talking to ourselves people.

Athena Vrentas Why do you bother to ask question when you have received numerous letters from so many people telling you over and over again what we want? You know exactly what we want and need. This is a facade! My question to you is, why are you even bothering to ask if you are too busy fighting us instead of trying to really understand this disease and help us? How can you live with yourselves?

Lisa Hilton And we lose another today
http://www.legacy.com/obituaries/nhregister/obituary.aspx?n=elizabeth-a-white&pid=155536727
Elizabeth A. White Obituary on New Haven Register
www.legacy.com
Online obituary for Elizabeth White. Read Elizabeth

Ronald J Berry Jr. I believe I have undiagnosed Lyme....PLEASE HELP....

Andrea Kujanek Thank you for posting the question. I think it is blatantly obvious what people "want" from IDSA based on over 2,300 angry remarks. Why the cover up with Lyme? Why the lack of acknowledgement? Why the denial? Why are insurance companies not chiming in? These stories are HEARTBREAKING. Patients have been put through the ringer with thousands upon thousands of dollars of unnecessary dollars on workups that include everything from CAT scans to MRIs to lumbar punctures to every blood test imaginable EXCEPT a Western Blot or the new blood culture. Why does a radiology report that shows white matter brain lesions not include possible Lyme as one of their differential diagnoses? Why list MS, and Systemic Lupus Erythematosis, and Avascular necrosis but not rule out Lyme. So while our health has been deteriorating over time and to the tune of thousands, you deny simple generic inexpensive ABX treatment. Treatment is not expensive. Oh wait, maybe that's your problem.

Roberta Jenny I'd like to see more doctors aware that Lyme can result from a culmination of disease-causing germs that aren't all susceptible to the standard treatment advised by your guidelines. I never thought I'd have to stop seeing my doctor out of the guilt I felt for getting more sick despite her doing all she could do without fearing backlash from the state medical boards. American citizens with health insurance shouldn't have to resort to buying meds overseas to get better, and doctors shouldn't have to put their licenses on the line to defeat this growing epidemic.

Debby Matthews It is so odd how the comment numbers are going down even though people are commenting constantly......All I know about the IDSA @ this point is that they are very good at pushing the delete button...Good work Cowards! Don't ask a question if you don't want to hear the answers, I learned that as a small child! Why don't you MAN UP and at least address some of these concerns????

Maria Angeles Gómiz Maillett Sign the petition to urge:
•The NGC to remove the guidelines as its listing rules require.

•The IDSA to revise its guidelines in a transparent process that includes both patient advocacy representatives and physicians who treat chronic Lyme disease.

http://www.Lymedisease.org/petitionscript/index.php

Carl Tuttle Please view the letter below referencing the outdated IDSA treatment guidelines:
Jan 25, 2012

Deputy State Epidemiologist
Division of Public Health Services
Department of Health and Human Services
29 Hazen Drive
Concord, New Hampshire 03301

Dear Dr Dionne-Odom,

My daughter applied for health Insurance through Anthem Blue Cross but was denied coverage because she has Lyme disease and Attention Deficit Disorder as a result of the infection. The Anthem Blue Cross health application actually lists Lyme disease even though the Infectious Disease Society of America claims that Lyme disease is easily diagnosed and treated. Strep throat is easily diagnosed and treated but we don't see that infection listed on the application.

Insurance companies are well aware that Lyme can be difficult to treat due to the claims they are experiencing as tens of thousands of patients remain ill after the recommended two to three week course of antibiotics. Insurance companies are denying coverage and reimbursement using the outdated IDSA narrow minded treatment guidelines as an excuse not to pay claims. There has never been any proof that persistent infection does not exist, none whatsoever. Current antibody tests only indicate past exposure.

Advanced Laboratory Services has developed a culture test for Lyme disease reporting positive cultures in 80% of symptomatic post treatment Lyme patient specimens. 90% of positive cultures have been found by day six and the remaining 10% after long term culture. Three university-based research groups, independent of the lab and from each other are presently in the process of duplicating this culture based on the methods of Advanced Laboratory Services. These institutions will publish their findings producing several publications validating this important diagnostic tool.

The denial of this epidemic and refusal to reimburse for treating persistent infection has caused untold pain and suffering not only in New Hampshire but across the nation.

The Anthem Blue Cross denial letter is attached to this email.
http://home.comcast.net/~runagain/Anthem%20Denial%20Letter.pdf
Carl Tuttle
33 David Dr
Hudson, NH 03051
Website: New Hampshire Lyme Misdiagnosis
http://home.comcast.net/~runagain/site/?%2Fhome%2

Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-Lyme-disease

Carl Tuttle Anthem Blue Cross health insurance application listing Lyme disease:

http://docs.anthem.com/wellpoint/docs/viewDocument?mcItemNbr=1373NH+D

Anita Hohendorf Kolbe "The denial of this epidemic and refusal to reimburse for treating persistent infection has caused untold pain and suffering not only in New Hampshire but across the nation." You're right, but the human suffering is not "just" in the U.S., they are suffering all over the world. The IDSA guidelines are applied everywhere and cause suffering without end. Please change it as soon as possible. You have the power

Sini Anderson Awareness, education and the treatment of LYME DISEASE by American doctors. IDSA revised guidelines so people can get treated. PLEASE, it's getting really crazy. It kind of walks, talks, and smells like the medical communities reaction to HIV / AIDS in the 90's.

Eric Higbie Change the Borrelosis (Lyme Disease) diagnosis and treatment guidelines. My neurological Lyme Disease was misdiagnosed as multiple sclerosis (MS). The misdiagnosis and MS drug Rebif has thrown me into my current living death. Have lost my career, my fiancé', and my chance to have my own family. These diagnosis guidelines are not fair to the patients of physicians.

I was under the impression that physicians truly, and in their hearts, felt strongly about their Hippocratic Oaths. The IDSA is making a mockery of the Hippocratic Oath. With my misdiagnosis and incorrect drugs, I am now house bound. No longer strong enough to sleep in my bed. Please change the guidelines and find a treatment that can restore my health!

Patsy Swinson I was also misdiagnosed as MS and Chronic Fatigue. My daughter was misdiagnosed as Fibromyalgia. My son was misdiagnosed as Reumatoid Arthritis. My husband was misdiagnosed as Chronic Fatigue. All because of the prevailing extreme ignorance of Lyme Disease, which we all have. We had to leave the state to find a real Lyme Disease expert to finally get an accurate diagnosis. Please educate yourselves and those who turn to you for information so the insanity can finally stop.

Kenneth Poindexter Carl Tuttle, that is amazing that BCBS includes this on their application. Of course, they aren't acknowledging that it exists. They want to know if you've been told you had it so that they can deny your coverage.

This obviously is an application for private insurance. Insurance companies are NOT allowed to do this if you are getting insurance through your employer

Kenneth Poindexter BCBS will NEVER admit though that they use this to deny coverage. We could test that however by simply submitting the exact same application with different name and address info with one checking the Lyme and the other not checking it. Its horrible that they would deny coverage to someone with Lyme disease or HIV even. WOW!

Tiffany Gonzalez How do you sleep at night knowing you're killing us by ignoring proper treatment of Borellia? Ignoring proper testing? Ignoring the human life that you all pretend to care about?!

Michele Wood Haynes We have posted our concerns regarding the blatant disregard for Lyme disease and co-infection sufferers. Let's start a letter-writing campaign. Let's flood their offices with letters and phone calls requesting that they remove the Lyme disease treatment guidelines until they can revise them:

1300 Wilson Blvd
Suite 300
Arlington, VA 22209
Phone: (703) 299-0200
Fax: (703) 299-0204

Kenneth Poindexter Michele, I've thought of this and unfortunately it will not solve anything. You can't plead your case with people that don't have hearts.

Ruth Thomas I personally am a victim of your outdated guidelines. Doctors following these took away two years of my life by refusing to diagnose and treat based on a positive IGenix test. Your pompous infectious disease doctor at Mayo Clinic denied the very existence of Lyme specialists, and refused to even do the Western Blot because my ELISA was negative, even with full clinical symptoms. Interestingly, a thyroid specialist has finally treated me with 4 months of antibiotics so far, and I have my life back! No more electric pokes, no more joint pain, no more bipolar symptoms, no more depression. I enjoy people again, and my brain works to plan and organize my life. Your guidelines are stealing lives. They MUST be changed!

Donna Zukaitis Falcone
Bahahahahaaaaaaaaaaaaaaaaaaaaaa! "The IDSA told the National Guidelines Committee that it had internally reviewed the guidelines in 2011 and decided they did not require change." Yup... cuz nothing new has been discovered at all...
LOLBAHAHAHAHHHAAAAAAAAAAAAAA! The fox is in charge of the hen house folks!
http://www.Lymedisease.org/petitionscript/index.php

Mark Thompson Just like the world is a sphere and not flat, persistent Lyme Disease is real and stole the health of my son. The Guidelines must be brought up to date, and more effective treatments developed.

Kenneth Poindexter
http://www.facebook.com/l.php?u=http%3A%2F%2Fwww.lymedisease.org%2Fpetitionscript%2Findex.php&h=hAQGzmddaAQFD5MCR8vQfAwnHUcwr3rkDYMTvU90e69AmsA
PETITION FOR IDSA GUIDELINES REVISION
www.lymedisease.org
REMOVE OUTDATED IDSA GUIDELINES FROM NGC
January 26 at 11:45pm · 2

Michele Wood Haynes Kenneth, we cannot solve this problem. We can only make enough noise that someone will be motivated to solve this problem.

Michelle Donaghey Take Lyme more seriously!! Get doctors to be more educated! My general practitioner doctor seems to think that a huge round bullseye rash and testing is the ONLY way to diagnose this disease- He did send me to Cleveland Clinic- but I believe because of the "tardiness" of doing this (months after horrible symptoms started, some which left me bedridden) I am left with constant intermittent ear popping, joint pain, numbness and tingling, etc! The tests themselves said that they are NOT the ONLY way a diagnosis can be made! If I didn't have Lyme, I would like to know WHAT I had- and why symptoms persist!

Jordan Fowler You know what you need to do you jerks. You know what's going on. YOU KNOW THE TRUTH ABOUT LYME DISEASE! Don't give the silent treatment. You don't get to do that. You are supposed to be professional Doctors. YOU KNOW. I know you take this home with you. You discuss this at your meetings. You talk about it with your colleagues. YOU KNOW WHAT THIS IS DOING TO MILLIONS OF PEOPLE! You are a society of AMERICA yet you won't stand up for AMERICANS! Why? What is holding you back from doing the right thing? I'm not the medical expert, you are. Deep down in your hearts, you know the truth. As humans caring for other humans, why won't you fix this? You do it for other infectious disease patients. You make it alright for them to get good treatment. You have the power to fix this. IF you don't, you know the burden will rest on your shoulders, on your hearts. YOU. KNOW. THE. TRUTH!

Eran Nils Redick *the IDSA can't help us, the Government will not allow them to, this Plum Island mistake we can forgive the government for, it was a mistake, but not acknowledging this and treating the victims of this bio-weaponized tick is irresponsible!*

Mary Shaffer yes the number of posts has decreased ... this is #2337, how many have been deleted ... I would be sure that would be hundreds deleted by the IDSA ... this is probably #3337 post!

Tracey Tice Siegel Integrity or at least accountability to the diagnosis and treatment of Lymes disease. Read your clinical trials. Shouldn't take AN ACT OF CONGRESS to simply treat patients fairly.

Patsy Swinson It's so much easier to just ignore THOUSANDS of desperate pleas for help, and to even delete them as if they never happened, than to face reality and do the right thing. Even if you are never held accountable in all your lives, you can be sure that God will hold you accountable. Of that you can be absolutely certain.

Eran Nils Redick the IDSA can't help us, the Government will not allow them to, this Plum Island mistake we can forgive the government for, it was a mistake, but not acknowledging this and treating the victims of this bio-weaponized tick is irresponsible!

Deb Wilson I am one of the lucky ones. After having a tick bite this summer I developed lyme disease. 2 wks of antibiotics did not resolve lyme disease. It's now been 3 months of antibiotics & I'm starting to feel some improvements. I couldn't imagine attemting to live with lyme not being treated like so many others.

Deb Wilson Please change the guidelines! Too many people suffer as a result.

Carl Tuttle Please read the following letter addressed to the New Hampshire Department of Health.

Jan 29, 2011

Deputy State Epidemiologist
Division of Public Health Services
Department of Health and Human Services
29 Hazen Drive
Concord, New Hampshire 03301

Dear Dr Dionne-Odom,

A new primate study identifies persistent infection after antibiotic treatment. This is yet again evidence that chronic infection is real and continues to be denied.

-Carl Tuttle

Aggressive antibiotic therapy could not kill all spirochetes in monkeys with disseminated Lyme disease
http://www.prohealth.com/library/showarticle.cfm?libid=16759

Article:
Persistence of Borrelia burgdorferi in Rhesus Macaques following Antibiotic Treatment of Disseminated Infection
– Source: PloS One, Jan 11, 2012
By Monica E Embers, Mario T Philipp, et al.

Abstract:
Rhesus macaques were infected with B. burgdorferi and a portion received aggressive antibiotic therapy 4 to 6 months later.

Multiple methods were utilized for detection of residual organisms, including the feeding of lab-reared ticks on monkeys (xenodiagnosis), culture, immunofluorescence and PCR.

• Antibody responses to the B. burgdorferi-specific C6 diagnostic peptide were measured longitudinally and declined in all treated animals.

• B. burgdorferi antigen, DNA and RNA were detected in the tissues of treated animals.

• Finally, small numbers of intact spirochetes were recovered by xenodiagnosis from treated monkeys.

These results demonstrate that B. burgdorferi can withstand antibiotic treatment, administered post-dissemination, in a primate host.
Though B. burgdorferi is not known to possess resistance mechanisms and is susceptible to the standard antibiotics (doxycycline, ceftriaxone) in vitro [in lab samples], it appears to become tolerant post-dissemination in the primate host.

This finding raises important questions about the pathogenicity of antibiotic-tolerant persisters and whether or not they can contribute to symptoms post-treatment.

Carl Tuttle
Hudson, NH 03051
Website: New Hampshire Lyme Misdiagnosis
http://home.comcast.net/~runagain/site/?%2Fhome%2F
Petition site:
http://www.change.org/petitions/subjective-symptoms-after-treatment-of-lyme-disease

Janet Hocking cure for morgellons aka NCS Neuro Cutaneous Syndrome

Helen House I would like for Morgellons study to be redone by competent and equality testing methods. Women were insulted in the CDC version. I do not remember ever being so ashamed to say I live in the USA.

Pamela Moore i feel as a Lyme Disease victim that there is a light at the end of the tunnel. We could get there if they would please please please change the guidelines.

Emilie Brittney Angel It's amazing how someone's death certificate reads as the cause of death as Lyme Disease. Wow, it was just so much in their head that it magically appeared there on their death certificate. That makes a lot of sense. Those that tested positive for Lyme and then died with that as the cause of death... How is that not evidence? There's plently more than just that too. I don't need to show you, everyone else already has. So what the heck?

Lj Noll It is hard to believe you are right that chronic Lyme doesn't exist when you profit so significantly from that line of thinking. Your research is circular, and offers nothing in the way of furthering anyones treatement. All it does is ask the same question over and over. If you have to prove your position over and over for 30 years, maybe your position is bogus. Its interesting how you always get the same results in your lab, but how other labs disagree with your findings. You would think there would be some conflict in the research, if it was genuine. Truth is self evident. Soon others will proove your tests inaccurate, your advise prehistoric and you will become irrelevant. A footnote in the history of corruption and ignorance. Already there is a new more accurate test for Lyme...your rule is slipping.
February 5 at 7:36pm · 2

Bobbyjoe Holliday I would like to see all the lies stop & actually see the truth though the trash

Latest comment as of the printing this document, Feb. 7, 4:14 am (eastern):

> **Carrie Freedom Gimbel Dillon** *All I want from society is to just get back to society and be a part of it. Because of your out dated guidelines, half of my doctors think I have one chronic disease, the others think I'm crazy, and one doctor thinks I have Chronic Lyme. I can't get everyone on the same page...I can't get the medical public to take me seriously when I am hospitalized, see the G.P. or any other specialist. You guys have ousted me from society. I just want to be normal, healthy and free.*

Obituaries

The Infectious Diseases Society of America (IDSA) suggests in its guidelines that Lyme disease is easy to diagnose and is easliy treated with three weeks of antiobiotics. The guidelines they control and dessiminate for other tick-borne infections also suggest that there is not much to worry about from tick- borne infections, or that there is not enough research yet to tell.

Yet, we continually maintain a list of US citizens and others who have died due to Lyme disease and its consequences upon the human body. <u>And this list is just the tip of the iceberg.</u>

Does the IDSA realize that each name on this list was someone's loved one, friend, family member? Do they realize each one of these people was once alive and full of hopes, dreams and goals?

Maybe they don't, but we do.

We dedicate this project to the following Lyme warriors who, in losing their battles, inspired us to fight on.

Dr. Carole M. C. (Paul) Alton
Carole a resident of Pepperell, died Sunday, Nov. 19, after a long battle with Lyme disease. She was the beloved wife of William J. Alton.

She graduated with a bachelor's degree in dental surgery from the University of Glasgow, Scotland in 1965, and a doctorate of medical dentistry from Tufts University in 1976. Mrs. Alton was a professor at Tufts Dental School through 2005. From 1978 to 1991, she had a dental practice on Main Street in Groton. She was a dedicated sports fan and particularly loved skating and New England Revolution Soccer.

According to family members, Mrs. Alton was involved in Dog Agility Competitions with her collie, Lola. She loved a wide range of music from Billy Idol to Rachmaninov. She had a wicked sense of humor, family members said. Besides her husband, she is survived by two sons, Paul M. C. Alton and Guy W. B. Alton, both of Mason, N.H.; a daughter, Pamela C. D. Alton of Nashua, four grandchildren, Ian, Winter, Renee, Camilla, and three step-grandchildren, Nicky, Rusty, and C.J. Published in the Lowell Sun on 11/24/2006.

James (Andy) Anderson
James was born in Bakersfield, and resided in Santa Barbara, California. He served in the US Coast Guard from 1968 to 1971, and then earned his degree in Business Finance from Cal State University in 1976. James was elected to "Who's Who in American Universities and Colleges" in the field of finance and was awarded the Wall Street Journal Award for Finance.

Anderson died November 18, 2006, after a three year battle with Lyme disease and Multiple Chemical Sensitivities illness.

Edward Arnold
Edward was born in Clinton, Tennessee November 26, 1951. He attended Vanderbilt University, becoming a Psychiatrist after 8 years of studies. Eddie especially enjoyed baseball, fishing, and reading about the Civil War. In June, 2000, he contracted Lyme Disease and had not practiced

medicine since. His last treatment was at Vanderbilt University.

Arnold died February 25, 2006, after a six year battle with Lyme disease.

Deiby Ashkenazy
Deiby contracted Lyme as a teenager visiting the USA. Back in Israel, when she became ill, she was misdiagnosed. Thinking she had autoimmune disease, she was treated repeatedly with steroids and got worse and worse. She became encephalopathic, went blind, became paralyzed below the waist and then developed arm weakness and bladder and swallowing difficulties. She finally was diagnosed with Lyme with a variety of positive tests on blood, CSF, and urine. Aggressive treatment helped her, but back in Israel she could not get this care.

June L. Anderson Atkins
June was born in Reiffton and was the wife of George T. Atkins for 45 years. June was a graduate of the Reading Hospital School of Nursing and worked at several hospitals before joining the U.S. Navy as an RN. She served at various Naval Hospitals both in the U.S. and overseas and is a Korean War Veteran. She resigned from the Navy as a Lieutenant USN (RN) to become a homemaker. She was very active with her community serving in many volunteer positions from Sunday school teacher to a docent for the Historical Society of Berks County.

Atkins died July 19, 2000 at the Berkshire Center where she had been a patient. Her body is being donated to medical research for study of Vascular Dementia and Lyme disease from which she died.

Beth Atkinson
Beth, age 61, of Fernindina Beach, Fla, passed away on December 29, 2011 in her home. Beth was a teacher and an environmentalist. Her motto was, “I believe my life can make a difference.”

Melinda Barrow
Melinda was 44, died at home on Friday, April 22, 2011. She is survived by her parents, Thurman and Mollie Barrrow; and brother, Mark of DeLand; daughter, Maria; and former husband, Kyle Furbee of Lakeland, Florida; as well as several uncles, aunts, and cousins. Funeral arrangements, which are currently incomplete, are under the care of Allen-Summerhill Funeral Home in DeLand.

Buck Roy Benoist
Looking at one of the last photos taken of Buck Roy Benoist, one gets the impression he was a fit man, not rugged in statute but rugged in looks, with a demeanor that implied he was a man of the American West. In fact he was-hailing from South Dakota and a member of the Lakota Indian Tribe, with a last name that hints he was partly a descendent of a one of the many French-Canadian trappers who helped settle that rugged part of the country. How he ended up in Exeter, RI is a story that started out in happiness for two people who found a late-in-life relationship and ended last August in tragedy, the latter caused by a tick carrying a disease.

His widow, Carla Neubert Benoist, still breaks down when she describes her husband's ordeal. Her only company in her Exeter home these days are three dogs which were part of the story as to how they met. Carla has always loved dogs and she loved to write poetry. Several years ago, she posted some poetry on the Internet and she got a reply from Buck Roy Benoist who happened to be visiting someone in Pennsylvania.

In the Internet chat she let him know that she lived with four big dogs--Carla has long been involved with greyhound adoption agencies. "His reply was that he wanted to meet me because he felt he could trust a woman who had four big dogs," recalls Carla.

Buck Roy Benoist was raised on his father's cattle ranch on the Cheyenne River Sioux Reservation. The ranch is now underwater, thanks to a hydroelectric project. Buck Roy eventually got a degree in watershed science from Western Washington University and spent a lot of time outdoors.

Buck and Carla were married in 2000 in a small ceremony conducted at URI where Carla was an office worker.

In 2001, Buck withstood a liver cancer attack and partly through a healthy diet rebounded. "He had lowered his blood pressure and cholesterol levels and we were eating a healthy diet with little red meat and much fish," she says. He enjoyed working outdoors in the yard of their modest Exeter home but what he really enjoyed, relates Carla, was substitute teaching in South Kingstown schools.

Buck was always careful when he worked outdoors, always conscious of ticks, says Carla. "He always checked himself and wore white socks," in order to spot any ticks. "I checked him too," she adds.

But then a couple years ago Buck started complaining that he would get tired easily. "He would go out in the yard and get tired from nothing," she said noting that Buck was not a big complainer. "He is one who would have covered up a broken leg-he had that western stoicism," she says. Buck visited the Narragansett Indian Tribe clinic (the Native Americans have reciprocal arrangements between tribes) saying he was feeling bad and could not explain it. The clinic referred him to the Veterans Administration Hospital in Providence (Buck was a Marine in the early days of the Vietnam War). Carla drove Buck up to the VA Hospital.

Buck's own theory was that he was having an angina spell and the VA doctors thought so too, said Carla. "His blood pressure was good, his cholesterol was down and all of his organs were good including his liver," she says. They decided to keep him overnight. She left him at the hospital at 2:30 in the afternoon.

"At 8:30 that night, he called and said they were keeping an eye on him and that he would see me tomorrow. That was the last time I talked to him." At 2:30 in the morning, Carla got a call from the VA Hospital that they were transferring him to Miriam Hospital for a whole blood transfusion "because he had a severe systemic babesia infection which they were unable to treat effectively."

"I got a lot of prayer chains going," says Carla who went right up to Miriam.

Buck was put on a respirator and medication to keep his blood pressure up and was kept in a drug-induced coma. He had two full blood transfusions-according to Buck's doctor "that's practically unheard of," Carla said. After about a week and a half, Buck suffered two strokes-they were not detected until two days later by CAT scan.

When Carla got the phone call about Buck's strokes, she was informed that 2/3rds of the left side of his brain was lost. She went into a room and screamed "No!" repeatedly for 10 minutes.

She called Buck's son and daughter-in-law in Oklahoma and they came to Rhode Island. The three of them were at Buck's side when life support was disconnected. He died on August 30 at 2:40 p.m., two weeks to the day after he was admitted to the VA Hospital. He was 66.

To this day, Carla does not know where Buck contacted the infected tick that gave him Babesia. It could have been in Washington State but when she contacted Dr. Thomas Mather, director of URI's Center for Vector-Borne Disease, he doubted that theory. The tick encounter could have been in their own backyard. "There was no tell-tale bulls-eye indicating a tick bite," she says. But with Babesiosis, there wouldn't be.

Carla believes the struggle Buck had fighting the massive Babesia infection triggered the strokes. "The burden of the treatment was just too much for his system." If he had survived he would have needed a trachea tube, would have lost the use of one arm and be confined to a wheelchair, says Carla. "He wouldn't want that."

Carla is quite familiar with tick-borne diseases through all her work rescuing dogs, especially greyhounds. She herself has had Lyme disease which she feels has left her with severe rheumatoid arthritis.

"It's sad-if it had been caught two months earlier, he might have survived. It strikes me that it was never detected," she says. "Someday, someone will come up with a good diagnostic system."

"I am also extremely determined that people should stop taking tick-borne diseases for granted or acting as if they were treatable and non-life threatening,"

Next spring, Carla plans to travel to South Dakota and visit Buck's favorite place to spread his ashes. In the meantime, she has nothing but praise for Mather's work in pushing the message that tick-borne diseases are preventable. "His is kind of a crusade. This is not a trivial disease-it is one that can happen to anybody." She admits it has taken her time to be in a frame of mind to be interviewed. But Buck's story may help people, she says. "I intend to do something and I am willing to talk to people. Buck would want me to."

Brian M. Bizier

Brian age 33, 1978 – 2011

NORTH BERWICK — Brian M. Bizier, whose motto – ‘it’s not about the parents, it’s about the children’ – inspired the lives of hundreds of troubled teens and children across Central Massachusetts and Southern Maine, died suddenly on Aug. 12, 2011, from complications related to Lyme disease, tragically cutting short his career as a clinical counselor. He was 33.

Remembered as a ‘passionate and gentle presence’ on the front lines of mental health care in some of New England’s toughest communities, Brian spent the past two years on a unique Counseling Services, Inc. program aimed at creating a broader vision of what counseling in Southern Maine could be.

‘When Brian spoke people listened because he was always so thoughtful with his words,’ said Nadine Fenderson, Brian’s project supervisor.

After earning a bachelor’s in Humanities from the University of New Hampshire in 2001, Brian rapidly honed his skills at New England mental health and substance abuse treatment providers, including Devereax and Sweetser. He earned a master’s in counseling from UNH along the way.

Admired by his colleagues and clients for his humility and open heart, in private life Brian also displayed great wit and often half-joked that he ‘looked for God his own way.’ But his love of reading and his bookshelves packed with philosophy, psychology and poetry classics showed the inspiration for mending lives came from the most profound sources. During his teenage years, Brian shined on the soccer and baseball fields of Hollis-Brookline High School in his native Hollis, N.H. Over time, he blossomed into a world traveler, versatile guitar player, World Cup soccer aficionado and self-taught gourmet cook, who passionately grew his own vegetables and herbs. He once said, ‘my garden is my church.’ Above all, he was a young family man.

Just four years ago, he and his wife of 11 years, Melanie, set-up a homestead in the rolling hills of Springvale. There he shared his gourmet touch during Christmas Day feasts that featured his special 10-hour cooked beef bourguignon & homemade tiramisu. The air at gatherings filled with magic when he played music with his daughter, Sierra. Brian lived a huge life in a short time. Those closest to him felt blessed to be near a true and young New England renaissance man.

Bryan Christopher Frydenberg Bower

June 28, 1982 – May 2, 2011.

Don’t follow my starlight
It goes well beyond and you must stay
and drift away until you too are gone
- Bryan Bower

Bryan was born in Oslo, Norway, on a half moon night to the delight of his parents, Jerry and Jia. At a mere 4 weeks of age he took his first bath in the ocean surrounding our summer house in southern Norway, safe in dad’s arms.

Bryan grew up with his family in Irvine, California, with frequent trips to see his dad's family and friends in Michigan. He excelled in school and was on the Woodbridge High School wrestling team. However, when he met rock climbers at the Master's College in Santa Clarita, he found his true passion. He could both lead and follow multiple-pitch climbs, always safe and never reckless, patient and encouraging to new climbers. Bryan could be trusted 100% and trained to scale the 3, 000 foot vertical face of El Capitan in Yosemite, a place he loved. His friends miss him enormously.

At some point, probably on his beloved island in Norway, Bryan was bitten by an infected tick and contracted Lyme disease. It was not diagnosed until several years later, by which time the illness had become chronic. The devastating disease invaded his nervous system and kept him in debilitating pain. But he wouldn't give up: he agreed to one invasive treatment after another, but the pain only grew. Bryan, whose name means warrior, fought like the lion he was. His last years confined him to his bed nearly all the time, in agony.

Bryan was an artist, a philosopher, and a poet. For love of his parents and all he knew he could give the world, he did battle against the overwhelming enemy for years after an ordinary man would have given up.

Peter Anthony Banducci

Peter was born on February 27, 1961 as one of six children. He attended school in the Mission area of Fremont and graduated in 1979. He studied automotive repair at a young age, and went to Ohlone College where he majored in business and met his future wife, Pamela. He went on to study many automotive courses and was an ASC certified Master Tech. On September 2, 1986, he independently opened Pete's Foreign Auto Repair. It is in its 21st year of business and continues to operate. Pete had the business certified as a Green Business and a AAA approved facility. His family meant everything to him. Some of his most enjoyable times were spent out on the boat with his family; celebrating family birthdays and holidays; baseball at Niles-Centerville Little League and was a big Giant's and A's fan; he enjoyed music, especially Michael McDonald and Chris Isaak; and last but not least he enjoyed his calls to his mom and Batman. Pete valued honesty, family, friends and the LORD and was cared for by his loved ones at home.

Banducci died September 28, 2006, after a long battle with ALS and Lyme disease.

Greg Bankert

Greg was born September 11, 1950 and was the beloved husband of Tanya L. Bankert, with whom he celebrated 28 years of marriage. Greg formerly was a self-employed remodeling contractor. Being an outdoorsman, Greg enjoyed hunting with his daughter and grandson, and his family and friends. He also enjoyed NASCAR, fly-fishing and going camping at Poe Paddy State Park where he was most recently a campground host. Greg liked his ice cream and going on shopping trips. He enjoyed using his hands and God-given talent to create furniture and crafts for his family and friends. Greg was a member of St. Joseph's Catholic Church in Dallastown, where he enjoyed singing in the choir.

Bankert died at his home October 29, 2006, after a long battle with Lyme disease.

* "He was a dear sweet man, who came faithfully to the York support group. Losing a husband and father to this disease is devastating." – Cathy Attig

R.Gordon Basinger

Mr Bassinger was born July 11, 1940. He was an esteemed member of the aviation industry for over 30 years, president first of Gordon Aviation sales and then since 1979, president of Phase Two, Inc. Prior to that, among other professions, he was an aircraft mechanic, avionics technician, flight instructor, and commercial pilot for Ozark Airlines. He was also accomplished in athletics, certified scuba diver, formidable racquet ball player, and 4th degree black belt and instructor in Shido-kan Shorin-ryu Karate. Basinger Sensei's longtime illness began in the 1960s with Lyme Disease. Since Lyme Disease had not yet been named or discovered at that time, he went untreated. He even checked into Mayo Clinic in the 1970s attempting to understand his symptoms, to no avail.

By the time he was finally diagnosed and treatment was available, the disease had advanced beyond the possibility of a cure. His immune system became more and more severely compromised and, therefore, paved the way for cancer which was diagnosed in 1997. He underwent various procedures and two years of chemotherapy, resulting in remission. In May, 2002, his cancer returned and had metastasized (spread). After several months of additional chemotherapy and much excruciating pain, on December 12th he was told he had but a few weeks to live. He still never gave up hope, faith or his commitment to battle illness. The evening before he died he said to his wife, "They don't think I can, but I'm going to beat this!" He was courageous, optimistic and determined to the end, which is no surprise to those who knew and admired this exceptional man. He will be painfully missed.

Basinger died December 27, 2002 of complications from bone cancer, secondary to Lyme disease.

Patricia Jones Bauman
Patricia an artist and animal lover and former longtime Wiltonian resident, was born in Philadelphia, Pa. She grew up in Wynnewood, Pa. Patricia attended Baldwin School and later graduated from Bucknell University with a bachelor of science degree in biology. A talented artist, avid golfer and animal lover, she illustrated a book written by her husband in the early 1980s called "Plants as Pets." The family tended to more than 800 plants in their Hearthstone Lane home, most of which were stored in their greenhouse like basement and a small attached greenhouse.

The book, published by Dodd Mead, advised plant owners to treat their greenery like pets. She was an accomplished watercolorist and became very interested in plants while her husband was working on his book. She eventually contributed 30 pictures that were used in the book, including one for the cover. "In order to draw them correctly, you have to look at them carefully," she told The Bulletin in an interview at the time. "It's a challenge." She and her family enjoyed summers in Kennebunk Beach, for more than 40 years.

Bauman died November 24, 2003 at her home.

Moonface Bear
Bear was a Golden Hill Paugussett Indian. He led a faction of that Connecticut tribe in an armed standoff with state officials in 1993, becoming for a time a symbol of American Indian defiance of authority.

Bear died on May 21, 1996 in a hospital in Norwich. The cause was leukemia, aggravated by Lyme disease, said his brother Quiet Hawk, the Paugussett's council chief.

Larry Bennett
Larry a former building inspector whose poor health had cost him his job and drained his finances was buried March 10 with the help of donations. By the time he was 50, Larry had been on life support three times, had several strokes, lost his job because of his health and spent all the money from his six figure income on medical expenses for him and his family.

Bennett died February 26, 2005 from complications of Lyme disease.

Dr. John Bleiweiss
A Lyme patient himself, dedicated his career to helping over 1200 of the most seriously ill Lyme victims return to productive lives. He researched and published many articles in medical journals that still define the standard for treatment protocols and lead the way to diagnosis for many. He was well loved and respected by his patients who traveled from around the world to see him.

Bleiweiss took his own life August 13, 1995, after being persecuted for treating patients with Lyme disease for seven years.

Billy Boesché
Born in Bear Creek, Pennsylvania. He was the owner of CleanUps Unlimited, a landscaping and hauling business. Billy enjoyed spending time at the beach in Ocean City, working around the house and was considered the family historian.
He was married for seventeen years to his wife Michele and will be remembered by many for his courage and kindness in the face of adversity.

Boesché died June 10, 2006, at his home in Highland, Maryland, from complications of ALS and Lyme disease.

Obituary published in The Washington Post on 6/17/2006.

Deborah Jean Bodden
December 08, 1951 - January 17, 2012
Age 60, of Milwaukee formerly of Union Grove, passed away unexpectedly at her home on January 17, 2012. She was born December 8, 1951 to Glenn and Lela (nee Vancil) Bodden in Burlington, WI. She lived her early life in Union Grove attending both Union Grove Grade and High Schools. She went on to attend UW Whitewater and worked as an Occupational Therapist at Southern Wisconsin Center. She had lived in Wheatland many years, and then had moved to Milwaukee 6 years ago. Debbie loved being around animals, especially her pets. Debbie was a caring person and was always there to help her elderly neighbors.
She also enjoyed crafts, gardening, fishing, sports, playing softball and was an avid Green Bay Packer fan. Debbie always treasured the time she spent growing up in Union Grove.

This Suicide Prevention page was made in memory of Debbie. http://whatislyme.com/if-you-ever-feel-suicidal/

Leo Bogart
Leo was a Polish-born, former U.S. Army Intelligence officer in World War II. He authored more than a dozen books and hundreds of media trade journal articles. Dr. Bogart served as the executive vice president and general manager of the Newspaper Advertising Bureau; taught marketing at New York University, Columbia University and the Illinois Institute of Technology; and was a senior fellow at the Center for Media Studies at Columbia and a Fulbright research fellow in France.

At the time of his death, Bogart was a director and senior consultant for Innovation, an international media consulting firm, and wrote a column for Presstime, the magazine of the Newspaper Association of America.

Bogart died October 15, 2005, ten weeks after being diagnosed with Babesiosis, a tick borne, malaria-like disease that destroys red blood cells.

Obituary published in The New York Times on 10/19/2005.

Judith Ross Boynton
Judith received her degree form the University of Pennsylvania and was a faculty member at Abington Friends School, the Ethel Walker School, Renbrook School and the Virginia Beach Friends School. She served as the head of the Town Hill School from 1992 to 1996. Wife to Richard FitzRandolph Boynton for 27 years, she also had two children.

Boynton died October10, 2004 at Sharon Hospital of ALS secondary to chronic Lyme disease.

Obituary published in The Republican-American on 10/13/2004.

Scott Brazil
A two-time winner at both the Emmys and the Golden Globes and was an executive producer and director of FX's series "The Shield". In addition to the Golden Globe for "The Shield," Brazil shared in two outstanding drama series Emmys and one Golden Globe for "Hill Street Blues" in 1983 and '84. Brazil also directed episodes of "Grey's Anatomy," "JAG," "Nip/Tuck" and "CSI: Miami," among others. He was a co-executive producer of "Gideon's Crossing" and "L.A. Doctors" as well. "Scott was a tremendous man, a loyal friend, a creative producer and the best director we had.

However, he rarely got the credit he deserved for all those things, because he never actively sought it out," says Shawn Ryan, creator of "The Shield." "The full range of his humanity and talents was fully known only to those of us who had the privilege of working side by side with him every day." Peter Ligouri, the former president of FX who's now head of FOX, says it was an honor to have worked with Brazil. "I cannot think of anyone who engendered more affection, admiration and respect than Scott," Ligouri says. "He fiercely guarded the creative vision of 'The Shield' and zealously supported and loved all of his associates. He never drew attention to himself, and he deserves the ovation that we have for him in our hearts." He continued to work on "The Shield" while fighting ALS, using a motorized wheelchair to get around.

Brazil died April 16, 2006 at Sherman Oaks Hospital in Los Angeles of complications from ALS (Lou Gehrig's disease) and Lyme disease.

"His loss is devastating to us personally and to the television industry, professionally." -Shawn Ryan

Obituary published in The BBC News on 4/20/2006.

Ellen Cary

Ellen was the daughter of Eric and Harriet Smith Cary, was born March 4, 2000 in Hannibal, MO. She was a first grade student who liked to fish, draw and play with her friends and family. She attended Park United Methodist Church and Mt. Pleasant Baptist Church.

Cary died May 23, 2007 at Children's Hospital in St. Louis after a 10 day infection with Ehrlichiosis.

"Ellen was a Beautiful Little seven year old girl that was so full of life and always thought of everyone else." -Harriet Cary

Jack Colenda

By Rebecca Sewald

Of all the things John Colenda aspired to do with his life, getting a tattoo was never one of them. But in early April, the 40-year-old Perryville resident found himself seated in a chair at House of Ponchos in Abingdon, Md., where he would leave later that day with his first tattoo. The artistic design that now encompasses Colenda's right shoulder is more than just a tattoo. It's a memorial to his son, Jack, who passed away suddenly last November from health complications after he developed Lyme disease. "A tattoo is not something I thought I would ever get, but under the circumstances, I decided I would do it, and I'm very pleased with the way it turned out," While pondering the design, he wanted it to be something that nobody else would have. His concept for the tattoo centered on his 8-year-old son's passion for lacrosse: "He played football and lacrosse, but he could never wait for lacrosse to start. As soon as football was over, he had his stick ready to go". He gave the tattoo artist, Josh Johnson, a picture of his son's lacrosse stick, shoes, helmet and gloves, which were incorporated into the design. "He even got Jack's name in there where he wrote his name on his gloves," pointing to the tiny letters that did indeed spell out "Jack." He wanted his tattoo to feature more than just his son's lacrosse equipment. "I thought it needed some kind of background," he said. "At Patterson's funeral home, they took his thumbprint because there are suppliers out there that can make jewelry with your thumbprint on it, and it just clicked – that was the background I needed."

Colenda contacted the funeral home and had a staff member send him an electronic image of his son's thumbprint. He printed the image and gave it to Johnson, who was able to sketch the print and include it in the tattoo's design. "This is a memorial that I can keep with me all the time," he said. In addition to getting a tattoo, he has been busy working on another project in honor of his son. He and his wife, Jennifer, are in the process of starting a foundation in jack's name that will benefit local children in need. The unofficially named JACK Foundation will stand for Just About Community and Kids, and explained that he is in the process of filing paperwork to have the name approved.

Bill Chinnock

Chinnock a resident of Yarmouth, Maine. One of the early founders of the Ashbury Park music scene, Bill’s five decade career as a singer-songwriter produced 13 albums and in 1987, won an Emmy. Chinnock was a self-taught innovator who, besides mastering the guitar and the harmonica, also made films and dabbled in computer graphics. He had his own studio and also worked as a producer. He was an advocate for other patients suffering from Lyme, a condition that affected both he and his wife.

Chinnock took his own life March 7, 2007, after an eight year battle with Lyme disease. “He was such an incredibly talented person, and a great brother, a beautiful brother. He was a funny, wonderful, entertaining guy.” – Caroline Payne

Obituary published in The New York Times on 3/9/2007.

Beth Coen
Beth was a resident of North Providence, Rhode Island. She was a history teacher at South Kingstown High School for 12 years until she became ill in 2004. Beth received an Associates Degree from Salve Regina University in Newport and graduated with a Bachelor of Arts, summa Cum Laude from Rhode Island College. She was also a member of the Board of Directors of the Holocaust Museum in Providence. In memory of Beth and her struggle with this devastating illness, her family has begun “Beth’s Quest”, a nonprofit foundation that is dedicated to promoting Lyme disease awareness and prevention.

Coen took her own life January 8, 2006, after a ten year battle with Lyme disease.

“We’re carrying on Beth’s work. It was her quest to bring Lyme disease awareness and prevention to the public.” -Rod Bowley

Dr. Jane Colfax
Jane Colfax made history by becoming the first female obstetrician-gynecologist to practice at St. Joseph’s Medical Center in Paterson at a time when female physicians were rare. After serving as an Army nurse during World War II, she attended Women’s Medical College of Pennsylvania and graduated in 1955. Colfax was very dedicated and it is estimated that she has delivered some 2,000 babies during her long career. She contracted Lyme disease during the 1980′s and went undiagnosed for years. Eventually, she had to give up her practice because she lost the use of her hands. Dr. Colfax was confined to bed for almost twelve years before she passed away.

Colfax died June 15, 2005 of a stroke, secondary to Lyme disease.

Kimberly Ann “Kym” Nagle Cooper
A resident of Columbia, Missouri. In her childhood she studied gymnastics, which grew into a lifelong love of modern dance. She was an accomplished swimmer and especially enjoyed her many visits to Finger Lake State Park and Rock Bridge State Park. In the summer of 2005, Kym rescued a small boy from drowning in a backyard pool. Before contracting Lyme disease, she served as a licensed practical nurse and is remembered for her kind heart and special skills as activities director working with senior citizens at Fayette Nursing Home. Kym is especially remembered for her love of family, music, dancing and the great Missouri outdoors.

Cooper died January 16, 2006, after an eight year battle with Lyme disease.

Vickie Crawford
Vickie’s life was devoted to education and children. She earned two Master’s degrees in the fields of Early Childhood Development and Physical Education, and a third in Library Media. She taught for several years before becoming the Librarian for four years at Athens Middle School. Her illness forced her into a medical leave and then early retirement.

Crawford died September 10, 2006, of complications stemming from Lyme disease

“She was a special person because of her commitment to education and her desire to make a difference with children.” – Joe Jackson

Alasdair Crockett
A resident of Brightlingsea, Essex in the United Kingdom. A University Professor and one of the country's top experts on modern life. Dr. Crockett held a Masters Philosophy degree from Cambridge and was a chief officer with the Institute for Social and Economic Research at Essex University. He had been suffering from depression caused by Lyme disease, which he believed he had caught during his time spent studying hill farming in Northumberland. A spokesman for Essex police said that Dr. Crockett had been exhibiting symptoms of extreme anxiety which is among the effects of the disease in its advanced stages.

Crockett took his own life September 14, 2006 after a difficult battle with Lyme disease.

Jon Williams Davis
PLEASANT HILL – Jon William Davis, 51, formerly of Covington, passed away Friday, March 4, 2011, at his residence in Pleasant Hill. He passed peacefully at home surrounded by the love of his family and friends, after a 10-year battle with Lyme Disease-induced illnesses.
http://www.dailycall.com/main.asp?SectionID=119&SubSectionID=205&ArticleID=171257&TM=70412.01

Dr. John Drulle
A graduate from the New Jersey Institute of Technology with a B.S. in Mechanical Engineering in 1967 before receiving his Doctor of Medicine. Dr. Drulle was a pioneer in the fight against Lyme disease and other tick borne illnesses, working toward educating the public about the need for prevention, treatment and research on tick-borne infections with special concerns regarding the effects of Lyme disease on pregnant women and the unborn. Because protocols were uncertain in the early days of this disease, he would never give a patient a medicine unless he tried it on himself first, because he himself was infected with Lyme as well as other tick-borne diseases. To say his practice was patient-centered is an understatement – he would go so far as to pick up prescriptions and deliver them to a patient's house when they were too sick to do so themselves. Even when he himself was battling chronic fatigue and pain, he kept a positive outlook and sense of humor. John Drulle was truly a blessing to all who knew him until he succumbed to Lyme. His many articles and presentations paved the way for proper diagnosis and treatment for all who were to follow.

Drulle died November 7, 2003 after a valiant battle with Lyme and co-infections.

Jeannette Eichelberger (Mamma Lyme)
We are sad to announce the passing of Jeannette of the Gettysburg TOFU Lyme Group. She died on Sunday, December 4, 2011 due to complications of Lyme Disease. She was known to our community and "Mamma Lyme". We will miss her greatly.

Herbert "Bart" Fenolio
Resident of San Marcos, CA
May 24, 1940-Dec. 16, 2010
Bart spent Christmas with Jesus. He came home from the hospital to his family with Hospice on December l6th, 2010, and passed away that evening with peace and joy. His wife of 46 years, Carol "Heidi" Fenolio, his daughter Joelle Grove & her husband Brian, and his son Dante & his wife Beth, brother-in-law Rick Hyde & wife Diane surrounded him with love as well as friends and grandchildren. He grew up in San Jose and Fall River Mills. He graduated from SJSU and married the love of his life, Heidi, in 1964. He & his sister, Brenda Albrecht, opened the first Dolphin Aquarium in l965 which was a huge success and built into the Dolphin Pet Village, which is still owned today by Brenda. Bart developed Dolphin Design, Inc, and began to custom design aquariums for hospitals, doctor's offices, and businesses in the Santa Clara valley. His love of meeting new people all the time and his love of the business made Bart so happy. His last project before selling his business was the Cupertino City Library salt water aquarium. He retired and moved to San Diego with Heidi to be close to new grandchildren.

Bart was diagnosed with Lyme Disease in August, 2009, after being misdiagnosed with ALS. He fought this horrific disease with strength and grace.

Angela Quinn Hausman
Angela had Lyme Disease. She was bitten by a tick in San Diego over 10 years ago. Doctors treated her for everything under the sun until she finally found a Doctor who specialized in chronic diseases. They almost immediately diagnosed her with Lyme Disease. She suffered for years and the stupid medical profession still won't admit to the world the devastating effects of that disease. Lyme Disease has now taken another life. She was 36 years old and leaves behind a great husband and two beautiful children. She was my pride and joy and I marveled at all her accomplishments during her short life. She was a magnificent daughter and I am so proud of her. I've never before felt the agony I'm feeling now.

Shea Hermsen
From Shea's Mom, Roxi~ Shea was an award winning videographer at age 7. Along with his older brother Bram, they placed first at the BC Student Film festival and best in the experimental category. They also sent their film "What's in a Puddle" to the Victoria independent film festival and won the "Silver Shortie Award". Shea played electric guitar. He loved the Beatles, (he was named after Shea Stadium where the Beatles played) he was learning Yesterday and he loved to perform. He also loved Reggae and wanted to travel to the Caribbean. Shea was an actor, playing Charlie Brown in the school play and he played soccer, rode his bike and was a strong and avid swimmer.

Shea loved science and created elaborate science projects. Ironically he even "participated" in his science fair the day he passed away. He loved science camps at the Vernon Science Centre, a place his grandparents founded. The name Shea means scientific and ingenious one and that fit him to a tee.

Shea had a great sense of humour and was a friendly sort, a "starry kind of guy" is how Shea described himself. He had lots of friends, got great grades and was very loving. He loved to play with clay, and build lego with his brother. He wrote stories and drew cartoons and made claymations and animations, of some of them. He played nintendo and used it to create his titles for his films and, of course, he loved computers.

The day before he passed away he asked me to "Double Pinky Swear" that I would not commit suicide. I hope that others will make their own "Double Pinky Swear" promise in Shea's memory. I kept my promise through Lyme and grief, today I am so much better and enjoying my granddaughter and grandson, who is so much like Shea.
Shea was a young boy, but an old soul.

If you are willing to take the "Double Pinkie Swear Promise" to Shea, please go here and sign the bottom of the page.
http://whatislyme.com/if-you-ever-feel-suicidal/

Terri Fishel-Hokit
Born October 15, 1945 in Escondido, California. In 1968, she moved to Capitola with her daughter. Terri worked at Cabrillo College and spent many years in the Title business in Santa Cruz and Santa Clara counties.

Terri died January 24, 2006 at Dominican Hospital in Santa Cruz, California, after suffering from Lyme disease and breast cancer.

Bryan Grimes
Bryan was a native of Washington, North Carolina. He graduated from the University of North Carolina in 1961 and became a commissioned officer in the USAF, serving for a period of time in Vietnam. He was self-employed in various businesses and started Time Foods Inc., with his wife and son in 1981. Bryan was a member of the Lyon's Club and the Toastmaster's Club and a lifetime member of the Full Gospel Businessmen's International. He went quietly through life and will be remembered by many for his kindness and many who never knew him benefited from his generosity.

Grimes died December 29, 2006 in Pitt County Memorial Hospital, after several years of battling Lyme disease.

Alex Hermstad
Sleep in heavenly peace beautiful, sweet, precious Alex. You fought the good fight and will receive your just reward …. Lori – you are a mother warrior beyond words, a hero and an inspiration … Jayci – you are a brave, loving, strong sister and Alex will live on through you … Till you all meet again in heaven, may God give you peace, strength, endurance and comfort in knowing that your baby is resting in the arms of Jesus. So much love and prayers are with you.
http://www.youtube.com/watch?v=mDZuvKvH5Ig

Brian Hirsch
Brian was born in Tampa, Florida and resided in McDonough, Georgia with his wife and children. He was a member of the Salem Baptist Church where he taught Sunday school. He played and coached sports and was an avid NASCAR racing fan. Brian was the owner of Eagle Electric and was known in the community as a colleague, not a competitor. His motto was "I can choose to laugh or I can choose to cry. I choose to laugh."
Hirsch died June 19, 2006, after a seven year battle with ALS and Lyme disease.

Carrie Chase
Born May 28, 1959, in Santa Ana, CA, went to be with her Lord and Savior on July 9, 2011.
Carrie graduated from Cal Poly, SLO with a teaching degree in Home Economics and received a Masters in Special Education. She began her teaching career at Vandenburg Middle School in the early 1980's teaching Home Economics and Science. She formed a state chapter of the Future Homemakers of America at VMS, which was so popular at school that it became the largest chapter in the state. Moving to the Hawaiian Island of Maui, Carrie taught for several years before returning to her home in Arroyo Grande where she taught science at Lompoc Valley Middle School. During that time several of her students asked her to start a Bible Believer's Club that was attended by many students. Carrie had a gift of reaching out to people, especially her students. They knew she genuinely loved and cared for them.

For the past five years, Carrie worked as a trainer with The Center For Teacher Effectiveness, and was recently promoted to director. She was a wonderful mother, daughter, sister and friend. She will always be remembered for her faith in Christ and her spontaneous zest for life.

Carrie is survived by her son Charles Robert Chase, her parents Robert and Carolyn Chase and her siblings Merril Allen, Marty Arismendi, and Bill Chase.

A memorial celebration of Carrie's life will be held on Monday, July 18th, at 1 p.m. at Grace Bible Church located at 100 Rodeo Dr., in Arroyo Grande. In lieu of flowers donations can be made to Lime's Disease Research in care of Carrie's family.

Michelle Heap
O'FALLON, ILLINOIS (KTVI-FOX2Now.com)
The sudden death of an O'Fallon Illinois paramedic has left the community stunned. 46 year old Michelle Heap was admitted to the hospital Monday and died the next morning. Officials suspect a tick bite may have killed her. Jeremy Sherman an O'Fallon Paramedic said, "Everything happened so quickly and she was gone the next morning it was just too fast."

Ted Hoggard
Ted was born November 5, 1982. He attended Butte College where he earned his credentials as an Emergency Medical Technician. His interests were many and ranged from competitive team roping to hunting, fishing, soccer and martial arts. He participated in pioneering research in the treatment for Lyme utilizing hyperbaric oxygen therapy, and was looking forward to managing the facility in Chico, California after completing his education.

Hoggard died August 19, 2004, after battling Lyme disease for many years.

Robert Jones
Robert passed away Dec 12, 2011 at 4 PM. Bob was quite ill with Lyme for many years and had to limit his activities according to his energy and strength. Early indication suggest a stroke or heart attack

that occurred while he was doing the daily word jumble. He died suddenly. He is survived by Barb and three kids.

Dillon King
King was born in Santa Cruz, California where he lived the rest of his life. He graduated with honors from UC Irvine and the Christian School of Ministry. His pursuits were health care, jewelry design, manufacturing and art. He also preformed many marriages for his friends.

King took his own life January 5, 2005, after suffering from severe complications of Lyme disease and Morgellons disease.

James Koch
A member for many years of the medical advisory committee for the Planned Parenthood League of Massachusetts, devoted his career to helping control population growth with the invention of the cervical cap. He was born in St. Paul and graduated from St. Paul Academy, receiving a bachelor of arts from Harvard College in 1951, and a medical degree from Tufts University School of Medicine in 1956. Researching in biological chemistry for many years, he then turned his focus toward the advancement of women's rights in work and advocacy.

Koch died February 13, 2007 in his home, following a series of strokes secondary to a severe case of Lyme disease.

Christina Lambeth
Christina was born July 8, 1980 in Forsyth County, North Carolina. She was a member of Hopewell Moravian Church.

Lambeth died February 10, 2000, after a long struggle Lyme disease.

Jon Pierre Lavallee
An athlete and an avid sport's fan. He was a gifted woodworker and craftsman, building furniture and restoring antiques. For many years, he was a motor-route driver for the Cape Cod Times delivering in the areas of Provincetown and Truro. Lavallee died June 19, 2002 at Beth Israel Deaconess Hospital in Boston of Lyme disease.

Jason Lee of Ingleside
Friends of the family of Jason Lee, 35, may visit from 4 to 8 p.m. Sunday, Jan. 2, at Strang Funeral Chapel & Crematorium, 410 E. Belvidere Road, Grayslake. The funeral service will be held at 11 a.m. Monday, Jan. 3, at the funeral chapel. Interment will follow in Avon Centre Cemetery in Grayslake. Born Nov. 15, 1975, in Libertyville, the pride and joy of Tom and Annette (nee Bohannon) Lee, he passed away peacefully at home Thursday afternoon, Dec. 30, 2010, surrounded by his loving family

John Martini
Born in Binghamton, New York, John resided in Plymouth, Massachusetts with his wife of 19 years. He was a former conservation expert, cab driver, chef, high school teacher and landscape business owner. John earned a degree in political science and American history from UMass- Boston in 1972. In 1985, he earned his teaching certificate at Southeastern University. John was well liked and eventually won an election for Selectman in his newly adopted hometown. He had many interests and talents, and was very active until he contracted Lyme while working outdoors.

Martini died July 24, 2005, after a devastatingly swift battle with Lyme disease.

"He was a family guy, warm, caring and wonderful, and he made you feel very special."- Michelle Turner

David McHoul
Mchoul was born in Boston, Massachusetts and resided in Provincetown. He was the Cape Funeral Home director since 1985, carrying on the family business. David also served in the Marine Corps during the Vietnam War. He enjoyed riding his bicycle around town and spending time with his many friends who loved his sense of humor. McHoul died June 6, 2005 at Cape End Manor Nursing Home from complications of Lyme disease.

Dr. Teresa Royer MacKnight
One of the founders of the International Lyme and Associated Diseases Society. She practiced medicine until being disabled by neurological Lyme disease. Macknight became the group's first president in 1999.

The Daily Item, Sunbury, PA: August 18, 2010
Dr. Teresa Royer MacKnight, 57, Andover, Maine
ANDOVER, Maine — Dr. Teresa "Terri" Royer Passed away on Sunday, Aug. 15, 2010, peacefully at her home in Andover. She was born March 25, 1953, in Lewisburg, Pa., a daughter of Russell and Louise Royer, of New Columbia, Pa.

She graduated from Lewisburg High School, Class of 1971 and received her Doctorate of Osteopathic Medicine, Des Moines University in Iowa in 1979.

Dr. MacKnight practiced medicine in Hollywood, Fla., Seattle, Wash., Negley, Ohio, and Beaver, Pa., before moving to Maine in 1990. She practiced medicine in Rumford until being disabled by Neurological Lyme Disease. She was one of the founders of the International Lyme and Associated Disease Society and the society's first president in 1999. As a lecturer and author, she strived to help the medical community and the public to recognize, treat and prevent Lyme Disease. Her desire to help others also took her to Barrow, Ala.; American Samoa and into rural areas where she was able to help those without access to medical care.
http://www.lymedisease.org/news/lyme_disease_views/531.html

Karl McManus
Karl was bitten by a tick in July 2007 on Sydney's Northern Beaches. A week later he developed flu-like symptoms but, due to a lack of knowledge about Lyme disease in Australia, the tell-tale signs and potential seriousness of the tick bite were overlooked. Karl passed away suddenly on 14 July 2010. His decline and death was due to a refusal by the medical system to accept he had Lyme disease and treat him accordingly. He did not want anybody to suffer like him ever again. Karl's full story can be found in the Karl's Story section of this site. http://www.karlmcmanusfoundation.org.au/

Patricia Myers Sullivan
Age 50, died Wednesday September 28, 2011 at her home in Ashburn, VA. She is survived by her husband James R. Sullivan and children Benjamin and Samuel Sullivan. She is also survived by her father William E. Myers, her sister Pamela Lindsay and brother William Myers, all of Westminster, MD. Patricia was devoted to raising her two teenage sons. She was an avid reader, and loved to play scrabble with close friends. Family will receive friends from 6 to 8 p.m. on Monday October 3, 2011 at Adams-Green Funeral Home, 721 Elden St., Herndon, VA where services will be held Tuesday October 4 at 11 a.m. Interment at Union Cemetery, Leesburg, VA. On-line condolences may be made at adamsgreen.com. In lieu of flowers, donations may be made to Galilee United Methodist Church, Sterling, VA.

Bill Nichols
Born in Ann Arbor, Michigan on June 10, 1949. He received his PhD in Chemistry from UCSD in 1985, where he continued his career in research chemistry. He loved swimming and will be remembered as a true friend and a fine scientist. Bill struggled bravely with the most severe complications of Lyme, but was kind and gentle to the end.

Nichols took his own life April 12, 2000, after a twelve year battle with Lyme disease.

Gary Norbut
March 5, 2008
Teresa called this morning.
It is with great sadness that I bring the news of Gary's passing early this morning around 3:45am EST.

Gary truly was a funny guy, always joking, telling his stories of his dogs and gardening, and of course could get somewhat irritated at all of us. That's what made him so special.

Know that even when Gary found out about his EC cancer, he was determined to beat it and from May 2007 until this morning, he sure damn tried. However during this last month of his life he started to suffer, so I am greatful to our Lord he took him so he would no longer suffer and he is at peace without any pain.

All our prayers should be directed to his family during their time of sorrow and grief.
I will post the funeral arrangements as soon as Teresa lets me know probably sometime later today.

Gary my dearest friend, Rest in Peace and know you were truly cared about from all of us. I know you can hear me - be happy now!
Love, Diane

Richard Olney
Richard was one of the first food writers to introduce the beauty of simple French country cooking to American readers with more than 35 books on food and wine. Born in Marathon, Iowa, Olney attended the University of Iowa before studying painting at the Brooklyn Museum Art School. He moved to France in 1951 at the age of 24, where he led a life of simple elegance surrounded by olive trees.

Olney died August 3, 1999, at his home, following a two year fight with Lyme disease.

Nancy Lower Orcutt
April 12, 1942 – June 28, 2011
Age 69, of Sarasota, formerly of Oak Island, N.C. Survivors include her husband, Bill; sons, David of Bethesda, Md., James of Montgomery, N.Y., Daniel of Silver Spring, Md.; her brother, David Lower of Syracuse, N.Y. and six grandchildren.

Amanda Reese
Amanda was committed to serving others during her young life. A graduate of Illinois State University and former YMCA camp counselor, she also served as a volunteer with AmeriCorps. Amanda led a team providing assistance to FEMA in Mississippi following Hurricane Katrina. She also volunteered for the Nature Conservancy’s effort to preserve the Florida Everglades.

Reese died November 19, 2006 from an enlarged heart stemming from complications of Lyme disease.

“Everyone who got to know her loved her” -Carole Reese

Thomas Roberts
Thomas grew up in Plainview, Texas. He was a former US Marine enrolled in the College of Visual and Performing Arts at Texas Tech University. He was very dedicated to his work, family and friends.

Roberts took his own life March 2, 2006, after a long battle with Lyme disease.

“He will be missed by everyone in Plainview. He was a vibrant life-loving young man.” -Lisa Kersh

Karen Johnson Rose
A co-moderator for LymeInfo since 2002, an internet group devoted to disseminating accurate information regarding tick borne illnesses. Both she and her husband, James, were very active with support and advocacy to the Lyme community. All who knew Rose found her as a warm and kind individual, always dedicated to her friends and family.

Rose died April 18, 2007, following a long battle with Lyme disease.
“Today, and for years to come, we will all have one thing in common… a broken heart because we’ve lost our Rose. I do know, however, the work Rose accomplished for the Lyme Community will live on forever. Her dedication to our cause has saved many lives and made many lives much better.” - Lucy Barnes

Joseph Sparacio
September 24, 1952 - October 14, 2011
His wife, Ann Ross Sparacio, also suffers from Lyme disease. Joseph worked for over a decade at the New York City Police Department.

Jim Sazani
Born September 5, 1943, in New York. He attended Texas A&M University and later served at Vandenberg Air Force Base with the Air Force. He was an engineer for 33 years and was active in youth sports programs and coached everything from basketball, baseball and football to girl's softball. Jim bred and trained driving horses for 18 years, but after Lyme disease, he was confined to a wheelchair.

Sazani died April 12, 2003 in Lompoc Hospital of complications due to a five year battle with Lyme disease.

"He never gave up. He was hopeful he would get through; there was always something going on in life that kept him alive." -Judi Sazani

A decorated Vietnam veteran, Bob Schneider resided on his small farm in Evanston, Indiana after retiring from Evanston State Hospital as a social worker. He was hospitalized for more than 25 days before his death with multiple organ and respiratory failure.

Schneider died August 2, 2006 from complications of Rocky Mountain Spotted Fever and Ehrlichiosis. Obituary published in the Courier Press on 8/20/2006.

Steve Philip Shears
Steve was born to Ray and Shirley Shears on Dec. 1, 1958, and died Dec. 22, 2011. He was raised in Fortuna and attended Fortuna Union High School. In 1976 he took a summer job on the Christie II, a commercial salmon boat, and found what was to become his life career. He crewed on a number of other vessels, including the Amy June, Aquarius, Lucky Star, and Miss Heather, then became captain of the Candy B in 1991. This important part of his life continued until the boat was bought out by the government in 2003. Steve tried other business ventures and jobs. He was happy, however, to return to the sea when the right fishing job appeared. In addition to work, he dedicated himself to helping others and did almost anything toward that goal. He loved God and was grateful to be 24 years clean and sober. He spent countless hours sharing with others and carrying the message. His seemingly endless energy, which often kept him in constant motion, turned into patience as he listened to friends and guided them with his gift. Lyme Disease interrupted his career and ultimately his life. He is survived by his treasured children, Jessica and Elijah; his brothers Greg and Doug; and a fellowship that mourns him deeply. A memorial service will be held at Trinity Baptist Church, 2450 Alliance, in Arcata at 2 p.m. Friday, Jan. 6, 2012. People are welcome to bring cookies or other light refreshments. Please sign the guest book at www.Times-Standard.com, click obits.

Vincent Sota
Sota was a Fire Rescue Engineer and an Emergency Medical Technician. After seeing more than fifteen physicians, Vincent was finally properly diagnosed with Lyme disease, but by that time, he was completely debilitated. Bedridden and unable to speak, his wife of eleven years, Mary, faithfully stayed by his side, maintaining hope until the end.

Sota died July 4, 2002, after a long battle with ALS secondary to Lyme disease.

Obituary published in the Times Publishing Company on 7/6/2002.

Oscar S. Strickland
Age 73, of Canton, passed away on Wednesday, June 22, 2011 in Aultman Hospital. He was born in Glenn, GA on March 17, 1938 to the late Baltimore and Lola Strickland. Oscar proudly served in the United States Air Force from 1956-1960. He retired from Republic Steel in 1999, following 36 years of employment. He was a member of Union Baptist Church where he proudly served as an usher. Oscar was a member of Colman Lodge #13 and was Patron of Lucile Ester Chapter #14. In addition to his parents, he was preceded in death by three brothers, B.G., Jesse C. and Albert Strickland; and a sister, Olphia Boykins. Survivors include his loving wife, Elizabeth Strickland; two sons, Larry and Dwight Strickland of LaGrange, GA; his daughter, Margaret Green of Franklin, GA; 10 grandchildren;

18 great grandchildren; three brothers, Charlie Frank (Geraldine) Strickland of Franklin, GA, Horace Strickland of Detroit, MI and Bobby (Georgia) Strickland of Canton, OH; and two sisters, Glema Bradfield of Cleveland, OH and Bernice Smith of Atlanta, GA. Funeral services will be Monday at 11am in Union Baptist Church, 413 Cornelia Ave. NE, with Pastor Sherman Martin officiating. Burial will follow in North Lawn Cemetery. Calling hours will be Sunday from 3-5pm in the Reed Funeral Home Canton Chapel, and one hour prior to the service from 10-11am on Monday in the church. In lieu of flowers, memorial donations may be made to the Union Baptist Church Building Fund. The family would like to thank the staff at the Aultman Hospital MICU. A special thank you to Roslyn Mack and Georgia Strickland for their love and support during these difficult days.

Erin Elizabeth Spillers
Beloved daughter, sister, aunt, and friend to many, Erin Spillers was born June 21, 1980 in Rapid City, SD. She died suddenly at her residence on Thursday, April 28, 2011 from complications of chronic Lyme disease. Cremation will take place at Southern Memorial Funeral Home and a Memorial Mass will be held at Our Lady Queen of Mercy Church, Montgomery, AL, on Wednesday, May 4, 2011 at 9:30 a.m.

Erin loved Alabama football, gardening, dancing, yoga, music, animals, and spending time with her many friends. She smiled through her pain and was always ready to lend a hand or an encouraging word to everyone she met. She will be deeply missed by everyone she knew. Though her years on Earth were brief, she lived them to the fullest, bringing joy to all who crossed her path. She was beautiful on the inside and out, with a smile that sparkled, a generous sense of humor, and a deep capacity for compassion and love.

She is survived by her mother and stepfather, Dr. Michael and Anne Marie Gormley of Montgomery, AL; father and stepmother, Frank and Kimberlee Spillers, of Atlantic, IA; brother, Mick Gormley, of Montgomery, AL; sister, Jessica Winum (Jarret) of Stanley, NY; grandmother, Phyllis Kertzman, of Rapid City, SD; aunts, uncles, cousins, nephews and nieces.

In lieu of flowers, contributions can be made in her memory to the Lyme and Tick-Borne Diseases Research Center, Columbia University, Att: Barbara Strobino, PhD, 1051, Riverside Drive, Unit 69, New York, New York 10032 or at https://giving.columbia.edu/giveonline/?schoolstyle=56437

Carole Tegnander
Carole born and raised in Valley Stream, New York, was full of life. Once she was diagnosed with Lyme disease, she co-founded the Long Island Lyme Association where she helped many by running support group meetings, giving educational seminars and testifying before the US Senate and various other committees to help raise awareness. She was an avid animal lover, a loyal and loving wife, a joyful and caring friend, and devoted mother and grandmother.

Tegnander died February 17, 2006 following a long battle with ovarian cancer secondary to Lyme disease.

“People who knew Carole saw she had an easy smile, was always up beat regardless of the pain she endured from two crushing illnesses. She lived her life by the motto, ‘NEVER QUIT.’” -Family statement

Obituary published in the Times Herald-Record on 2/19/2006.

Christopher Thomas
A resident of Annapolis, Maryland and a sound engineer for feature films, television shows and music videos. He was a graduate of Montgomery College and owned the firm, CPT Sound Services Inc. Christopher enjoyed both history and travel, and his career allowed him to delve into both passions. In 1990, his work earned a Capital Region Emmy Award. Thomas died May 3, 2006 at Anne Arundel Medical Center, from complications of a five year battle with Lyme disease. Obituary published in The Washington Post on 5/9/2006.

Jenny Umpress
Jenny contracted Lyme disease when she was 15 years old, and spent the remainder of her life fighting to find the strength to overcome numerous obstacles and hardships. The disease left her bedridden and in terrible pain. It also caused complete amnesia from which she never recovered. The physical devastation was exceeded only by the emotional turmoil placed on her by misinformed and unsympathetic physicians who did not understand the nature of her illness. Still, her goal was to try and help other patients from experiencing the same fate.

Umpress died August 26, 1994, after a six year battle with Lyme disease.

Carole A Van Doorne
CRYSTAL LAKE – Carole A. Van Doorn, 43, of Crystal Lake, passed away Feb. 12, 2011, at home surrounded by family after a courageous battle with ALS.

She was born Sept. 21, 1967.

She is survived by her beloved husband of 18 years, Dean Van Doorn; her loving children, Rachel, Joseph and Elizabeth; her cherished parents, Bruno and Patricia Grund; her dear brother, Dan (Heather) Grund; her mother-in-law, Sharon Van Doorn; her father-in-law, Bill Van Doorn; her sister-in-law. Nicole (Brad) Schwan; her brother-in-law, Dave (Nancy) Van Doorn; and many dear friends. The visitation will be from 2 p.m. until 8 p.m. Monday, Feb. 14, at Davenport Family Funeral Home, 419 E. Terra Cotta Ave. (Route 176), Crystal Lake. The visitation will continue from 10 a.m. Tuesday, Feb. 15, until the 11 a.m. service at Willow Creek Community Church, 220 Exchange Drive, Crystal Lake. Interment will be private. In lieu of flowers, donations may be made to the Carole Van Doorn Memorial Fund, Homestate Bank, P.O. Box 1738, Crystal Lake, IL 60039.
Online condolences may be left for the family at http://www.davenportfamily.com/.

Colonel Bryce H. Wagner
Born October 10, 1943 in Lenoir, North Carolina, Bryce Wagner received his Masters Degree at Central Michigan in 1984 and was a War College graduate. After serving 26 years in the United States Army, he retired a full military colonel.

Wagner died June 7, 2006, after a long battle with Lyme disease.
Obituary published in the Topeka Capital-Journal on 6/13/2006

Leslie Rae Wermers
7/7/1967 – 11/2/2008
The Lyme community has lost an important hero and friend–and so did I. Leslie Wermers, 41, died from heart failure in her sleep on November 2nd. It’s hard to imagine Leslie’s heart giving out, because for anyone who knew her she was all heart. A dear friend to so many and a tireless worker on behalf of the Minnesota and national Lyme communities, Leslie gave everything she had to help others who were sick. And everything she had was an abundant reserve of love and support–even as her own health waned.
http://lymebook.com/blog/news/leslie-wermers-tracie-schissel-minnesota-lyme-fighters/

Betsey White
WHITE, ELIZABETH A. Elizabeth A. White, age 73, of Trumbull, daughter of Charles J. White and Helen Campbell White, died on Saturday, January 14, 2012. She was born on September 6, 1938 in St. Vincent’s Hospital, Bridgeport, CT. A Lauralton Lifer she graduated in 1956. From her parents, she inherited a generosity of spirit, an Irish can do happy spirit, quick sense of humor, gift of gab, love of politics and socializing. She loved summer vacations at Lake Winnipesaukee with family and friends-swimming, diving, rowing with the other kids was always wonderful. Childhood loves included ballet/pointe, biking and swimming. A charter subscriber to Long Wharf Theater, her more recent retirement interests included Metropolitan Opera simulcast HD presentations, James Joyce’s Ulysses/Bloomsday event at UCONN. An apt description was given by her fellow eighth grade classmate Vicki Foder at a graduation

exercise “Laughing, talking, full of fun she has a smile for everyone.”

Following a third generation family tradition she entered the field of nursing, graduating from Boston College School of Nursing, cum laude in 1960 with a Bachelor of Science. After pursuing an interest in community mental health/psychiatry, she entered the University of Pennsylvania Psychiatric Nursing Program in 1968 where she was inducted into Sigma Theta Tau, national honor society based on first semester academics, earning a Master of Science in Nursing in 1970. Continuing her clinical training she enrolled in the Family Training Program at the Center for Family Therapy, while also being enrolled in Veteran’s Administration Assistant Chief Nurse Traineeship. In 1998, she completed her 2 year post masters’ family nurse practitioner program at Fairfield University. Miss White holds ANCC certifications in Family Nurse Practice and Psychiatric Clinical Specialist. She also held the ANCC certification in Nursing Administration. Her nursing experiences have included clinical, psychiatric, public health, administrative and teaching. Her first love has always been direct clinical treatment. Her early mentors provided her with excellent exposure to innovative treatments aimed at improving the quality of patients’ lives.

No one loved a fund drive more than Betsey. She loved searching for bargains negotiating with food stores for the best prices on bulk purchases for the Thanksgiving drive at Lincoln-Bassett School. She had a wonderfully generous team that widened with each year. The grounds crew from the West Haven VA Hospital provided the truck transportation and the staff were available to collect and distribute the gift baskets to identified families in great need. That was only the beginning of the holiday donations. It energized the Christmas donation for the fourth and fifth graders. The drives started out as a nursing project and expanded throughout the hospital as an annual event that was engaged by all the hospital services. Her teacher friends worked with the second graders from Daniels Farm School in Trumbull who made Christmas drawing decorations for each named child’s gift bag. The Monroe Trail Troop generously wrapped over 1,000 gifts each year. In addition to warm winter clothes, a toy, and candy, Betsey was instrumental in procuring watches for each of the children from Timex. The gifts were delivered by Santa’s truck (From the VA) and a gala distribution complete with music and Santa took place at the school. Each individual child was called up to receive their gift from Santa. It made them feel so special. Betsey had a gang of do gooders, staff members, sales people, bargain store owners who were always on the lookout for bargains year round. These drives would never have been successful or have been possible without the wonder staff of the WHVA. Betsey was known for her generosity of spirit and was always willing to lend a helping hand. For the last ten years of her life, she has dedicated herself to the cause of Lyme Disease.

She has been determined not to let this condition lead to dysfunction in her life. Whenever possible, she was available to other patients offering support and encouragement. In an attempt to learn as much as possible, Ms. White engrossed herself in current Lyme medical literature/publications, attended International Lyme and Associated Tick Borne Diseases, and supported the University of New Haven’s research and annual symposiums. Betsey would like to express her gratitude to her special friend Marilyn McCarthy who has been at her side throughout the most acute life threatening stages of her illness and to Susan Falkowski, her goddaughter who during a difficult period in her own life assumed responsibility for health care advocate and Mary Lou Sheehan who was present every day fighting the ice and snow of the worst winter to feed Tobie the cat.

Travis Wilson

Travis was born December 29, 1982 in Olympia, Washington. Travis attended Austin Community College and had just found financial backing to start a new business of fixing computers. He was an avid reader and writer and wrote many poems. He became a certified pharmacy technician in 2003, using his knowledge of Lyme and Morgellons to help other patients. Travis was very sick for much of his life but fought bravely through it all.

Wilson died April 23, 2006, from complications of Lyme disease and Morgellons disease.

Obituary published in Hill Country News on 5/3/2006.

Jay Thomas Wolfenden
56, of Westminster, died Wednesday, Aug. 17, 2011, at Carroll Hospital Center. Born Jan. 12, 1955, in Baltimore, he was the son of the late John Thomas and Shirley Leach Wolfenden. He worked at Shoppers in the seafood department. He was an Eagle Scout with Troop No. 56 and was co-coordinator of the Central Maryland Lyme Disease Support Group. He also was an avid fisherman, Ravens fan, and enjoyed cooking. Surviving is a sister, Robin Ann Wolfenden, of Westminster. A graveside service will be held at 10 a.m. Thursday at Zion United Methodist Church Cemetery, 2716 Old Washington Road, Westminster, with the Rev. Marianne Sickles Grabowski officiating. Memorial contributions may be sent to Carroll Hospice, 292 Stoner Ave., Westminster, MD 21157. Arrangements are by Pritts Funeral Home & Chapel in Westminster. Sign this guest book online at www.carrollcountytimes.com

Donna Marie Zakszeski
"Zak", of Beverly passed away Friday at the age of 50, after bravely battling Lyme disease and Breast Cancer for several challenging years. Donna was a graduate of Burlington City HS, class of 78′. She went on tobecome a Registered Nurse, while settling in Maine. Donna loved to read, learn new things, garden, the ocean and practicing yoga. Most of all, she loved her family. She is survived by her children; Justin Spencer (wife Julie), Jennifer (husband Thomas Dunn), and Jordan Spencer (s/o Christopher Blake), their father Rick Spencer and by her siblings, Charles (wife Sharon), Scott (wife Linda) and Lynda Zakszeski (s/o Andrew Newsome), and Patricia Kramer (husband Kirk) and now rests peacefully with her father Charles, mother Eleanor "Ellie" and brother John "Jack" (husband to Patricia R. Zakszeski). She was extremely proud of her grand children; Cody, Chloe, Max, Casey and Zak (due in November). Her many nieces and nephews, like all who knew her,loved and admired Donna for the wonderful person and amazing woman that she was. Donna can be remembered most for her breath taking smile and infectious laugh. She was beloved by those close to her and will be greatly missed.

Lori Hall-Steele
Lori, who died Wednesday Nov. 19, 2008, reflected on those words often in her 44 years and tried to live her life that way: without a formulaic approach to it and undaunted by the fate we all face. A yearlong battle with a mysterious illness and her subsequent death did little to dim her huge love of life, dampen her infectious laugh, detract from her gifts as a wonderful writer or diminish her affection for her many friends, her family and her beloved son, Jackson.

Lori was born Sept. 1, 1964, in Flint. She graduated in 1982 from Davison High School and attended Michigan State University where her budding talent landed her on the staff of the Michigan State News. She developed her craft covering the Michigan Legislature, the wedding of Prince Andrew and Sarah Ferguson in London and South African leader Nelson Mandela's initial visit to the U.S.

After graduating from MSU in 1986, Lori worked at the Center for Investigative Reporting in San Francisco. She returned to Michigan to work at the Albion Recorder and then the Traverse City Record-Eagle from 1989 to 1993. After losing her dear sister Marci in a 1995 auto accident, Lori launched a successful award-winning freelance career, including editing Michael Moore's book "Dude, Where's My Country?" and penning her own, "Sweet and Snappy Cherry Drinks." She also wrote essays for publications ranging from the Washington Post to SmartMoney and Woman's Day.

Besides reading and writing, Lori loved to travel. That passion led her to points far and wide, including trips to Australia, Mexico, the United Kingdom, France, the Czech Republic and 48 of the

50 United States. One of her favorite travels was to Dunvegan Castle on the Isle of Skye, Scotland, ancestral homeland of clan McLeod.

Lori married Brian Steele on Feb. 11, 1989, and gave birth to her greatest creation, son Jackson Gabriel, on Aug. 6, 2001. She is survived by and will be greatly missed by both.

Other survivors include mother Shannon K. Hall, whose selfless devotion to her daughter allowed Lori to enjoy every last moment of her life; beloved siblings David Lee Hall and Tonya Manning (and sons Tyler and Trevor Manning) of Cedar; Timothy Grey Hall (and daughter, Zoe Milagro Hall) and Breanne Russell of Traverse City; and Teresa Sullivan (and daughters, Alia Warner and Megan Sullivan) of Williamston; aunts Penelope (Russell) Neimann, Maurine McLeod, Tina (Mike) Hood; uncles Jamie Lytle and Chris (Tracy) Lytle; uncle Gerald (Alice) Hall; favorite cousin Andrea Unsel and her partner, Nancy Penny, as well as numerous other cousins, family, friends, and a network of writers and artists who spanned the globe. She was predeceased by her father, Donald Lee Hall, sister, Marci Lynn Hall and brother-in-law Thierry Coulet, of Ste. Maxime, France.

Throughout this past year, so many people came forward to help Lori in every possible imaginable way. She called these her “white light people,” including brothers Dave and Tim, Tonya Manning, Breanne Russell, Maurine McLeod and family friends Phil Clyne and Kris Hains who worked tirelessly on her behalf. The family expresses their deepest gratitude.

In lieu of flowers, memorials may be directed to a fund established in the name of Jackson Gabriel Steele in care of Northwestern Bank in Traverse City.

Visitation will take place on Monday evening, Nov. 24, from 5 to 8 p.m. at Reynolds-Jonkhoff Funeral Home in Traverse City. An 11 a.m. memorial service is planned for Tuesday, Nov. 25, at Baypointe Community Church in Traverse City.

US Political Figures Diagnosed with Lyme Disease

Berkley Bedell, former US Congressman (D-IA)

Philip Norman "Phil" Bredesen Jr., former TN Governor

George W. Bush, former US President

Chris Harris, TX State Senator (R-Arlington)

Glenn McConnell, SC Senate President

George E. Pataki, former NY Governor

Merle H. Phillips, retired PA House member

Todd Rock, PA State Representative

Charles Schumer, Senator (D-NY)

Christie Todd Whitman, former NJ Governor, former

Administrator of the Environmental Protection Agency

Joe Wilson, US Congressman (R-SC)

Public Figures Diagnosed with Lyme Disease

Jane Alexander, actress/author

Alec Baldwin, actor

Lisa Bevill, Christian singer

Christie Brinkley, model

Joseph Burrascano, MD, Lyme disease treatment pioneer

Tom Carson, former Manitoba Deputy Minister of Health

Neneh Cherry, singer

Bill Chinnock, musician (Lyme drove him to suicide in 2007)

Mel Clarke, archery champion

Brandilyn Collins, suspence novelist

Mary-Lynn Currier, marathoner

Joshua Daniels, NCAA basketball player

Ryan Dunn, of MTV's Jack Ass series

Nick Esasky, former baseball player

Perry Fields, track and field athlete

Michael J. Fox, actor

Julie Furtado, professional cyclist

Richard Gere, actor

Daryl Hall, musician

Pete Harnisch, former Major League Baseball pitcher

Ally Hilfiger, daughter of fashion designer Tommy Hilfiger

Rob Hill, Target-Chip Ganassi Racing team crew chief

Ashley Cooper Kerns, daughter of actress Joanna Kerns

Rob Kress, former Detroit weathercaster, WXYZ

Wanda Kurdziel, hiker/backpacker

Brooke Landau, Today Show reporter

John Lurie, actor, musician, painter, director and producer

Irene McGee, former cast member of MTV's "The Real World"

Tara McMenamy, three-time All-American cross country skier

Ray Mears, British Survival guru

Joe Meeko, Mr. Universe/Mr. America/Mr. USA (died at age 48 of Lyme disease in 2009)

David Mennes, MMA fighter

Debbie Morgan, actress

Krissy Nordhoff, Christian singer, songwriter

Chuck Norris, his wife Gena, and their children

Carrie Nye, Dick Cavett's wife

Pamela O'Kane, triathlete

Chelsea O'Donnell, daughter of comedian Rosie O'Donnell

Lembit Öpik, former Member of British Parliament

Gary Player, pro golfer

Parker Posey, actress

Christie Rampone, USA women's soccer

Kevin Salem, musician

Peter Sarsgaard, actor

Tom Seaver, former New York Mets pitcher

Pete Seeger, folk singer and activist

Wyatt Sexton, NCAA quarterback for the FL State Seminoles

Jamie Lynn Sigler, actress

Tracey Silver, actress

Tim Simpson, pro golfer

Martha Stewart

Ben Stiller, actor, and his son Quinlin Dempsey Stiller

Samantha Stosur, tennis pro

Amy Tan, author

Thalía, Latin singer and actress

Randy Travis, musician

Christy Turlington, model

Diane Varsi, actress

Alice Walker, Pulitzer Prize-winning author

Pamela Weintraub, author/science writer

Rebecca Wells, author

Cody Willard, Fox News anchor

Leila Zackrison, MD

Michael Zaslow, actor

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Jessica Wheeler

And all who bravely voiced their concerns through their incredibly powerful, meaningful and knowledgeable comments.