

TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 15 | August 2014

A portrait of Brett Wiscons, a man with dark curly hair, smiling and wearing a light blue button-down shirt. He is holding a guitar, which is partially visible on the right side of the frame. The background consists of a wall of stacked logs.

Brett Wiscons
opens up about ET

Understanding
Primary Writing Tremor

Fall Scholarship Award Winners

ET Research Updates

Learn what's being funded and
how to get involved

ietf International
Essential Tremor
Foundation
Your Voice for Essential Tremor

Thoughts from the Executive Director



This issue is full of inspiring stories from many young individuals who are all challenged by ET. Brett Wiscons, a musician, song writer and author describes his choice to stop hiding his tremor. He shares with us the decision to accept his tremor and overcome the challenges he experiences in living out his goals and dreams. As you will see, Brett describes this as his “new” normal. Perhaps some of you have experienced the same and will identify with his story. If you do, I encourage you to reach out and contact Brett to share your story with him. It will not only bolster his resolve of living with his “new” normal but may also be a great inspiration for you in living out your dreams.

Don't forget to read about the incredible students who received IETF scholarships for the coming fall semester. These students are definitely paving the way for a better tomorrow and doing so much good in their communities and around the world. While they have ET, nothing is stopping them from reaching their goals. We wholeheartedly applaud all that they have accomplished and will achieve in the future.

And you'll get a glimpse of the future of medicine when you read about the exciting world of nanotechnology and what possibilities lay ahead for all of us. It is absolutely amazing science and will undoubtedly capture your imagination of what is possible when new technology is used to better the lives of patients.

We have many upcoming patient-centered events planned for this fall. Be sure to check the list on the IETF website at www.essentialtremor.org/seminars to see if we're coming to a city near you. In addition, we will be attending the Gerontological Advanced Practice Nurses conference in September and the American Academy of Family Physicians Scientific Assembly in October, to educate healthcare providers about the needs of ET patients and provide them with current information.

We are currently working on plans for a Walk in March for ET Awareness Month. The information about this walk will be posted in September, so be sure to check the IETF website to learn more about how you can participate. We want to get started early this year to gather as much support as possible in this concentrated push to increase awareness and educate the world about ET. So now is the time to get a commitment from your friends, family and co-workers to walk with you in March!

We have received many calls recently asking about research trails and participation. This issue of *Tremor Talk* contains information on a few new research opportunities, including more information about the Focused Ultrasound research trial. Take this opportunity to learn more about what ET research is being funded by the IETF thanks to your generosity in giving this year. Check the IETF website frequently and the TremorTalk.org blog where research trials and findings are posted as quickly as we receive them. We thank you for all your support. Headway is being made because of all of you!

Many thanks for all of your support this year. We are heartened by your commitment to donate, volunteer, spread the word, educate and support each other. We look forward to another great four months and will continue to work tirelessly on your behalf.

Sincerely,

A handwritten signature in cursive script that reads "Catherine Rice".

Catherine Rice
Executive Director, IETF



International Essential Tremor Foundation

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Cover Photo: Brett Wiscons Photo Credit: Kurtis Bowersock

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Please send comments, questions, and story ideas to: IETF *Tremor Talk* Editor, PO Box 14005, Lenexa, Kansas 66285-4005 USA or call toll free 888-387-3667 or email info@essentialtremor.org.

This publication is not intended to provide medical advice or be a substitute for qualified medical care. Appropriate treatment for your condition should be obtained from your physician. The content of this publication offers information to those with essential tremor. The IETF does not endorse any product advertised in this publication unless otherwise stated.

In Memory of Doug Ward Leader. Volunteer. Friend.



Doug Ward

It is with a heavy heart that we report the passing of William Douglas Ward, of Glen Ellyn, IL, on July 3, 2014. Doug truly loved to give back to his community and was an active member of the United Methodist Church, the Kiwanis Club of Glen Ellyn, the Glen Ellyn Historical Society, and the Morton Arboretum where he was a docent. Doug founded and acted as leader for the Glen Ellyn Essential Tremor Support Group in memory of his mother, who also suffered from severe essential tremor. He spoke out about ET and the IETF at numerous health fairs, services clubs, and retirement communities; raising awareness wherever he went. Doug also served several years as a dedicated member of the IETF Board of Directors.

Doug loved his community and the world around him. He was a lifelong student, especially interested in science, history and family genealogy. Doug spent 20 years working as a high school biology teacher, as well as serving a term as president of the Michigan Education Association. He completed his PhD in education from Michigan State University in 1973, and for more than 20 years he was Director of Education for the American Osteopathic Association.

Doug was a caring husband and partner to his wife, Ruthann, for 57 wonderful years; loving father of the late Catherine Medecke, Laura (Ken) Hanks, Diane (Martin) Meyer; dear grandfather of Andrew (Jill) O'Neal, Douglas Murray, Carrie (Ben) Herrera, Alyssa (Tyler) Reaves, Joel Hanks, Allison, Stuart and Lauren Meyer; great grandfather of five great-grandsons; compassionate brother of Dr. Robert C. (Helen) Ward and Peggy (Sam) Scalzo; and adoring uncle to many nieces and nephews.

His compassion and leadership will be dearly missed. ☺

“Unselfish and noble actions are the most radiant pages in the biography of souls.”

~David Thomas

Estate Planning

Estate planning is the process of thoughtfully providing for the efficient transfer of your assets to your heirs and charitable organizations in accordance with your wishes. It is a testament that affirms not only how your estate will be distributed, but also what kind of a legacy you will leave behind for future generations. A good estate plan will help you make certain your intentions are clear.

Estate planning isn't just for the super rich or older people. Everyone should do it. The planning process can begin with simply writing a will, but it can also involve any or all of the following:

- Establishing a trust
- Changing beneficiaries of life insurance policies and retirement accounts
- Selecting guardians for minor children
- Providing lifetime income for yourself and others
- Minimizing taxes and other estate settlement costs
- Passing on business interests
- Providing for your charitable interests (like the IETF)

Estate planning is not a do-it-yourself project. You'll be faced with critical decisions that only a professional estate planner can help you make. Contact The National Association of Estate Planners & Councils (NAEPC) at 866.226.2224 or online at www.naepc.org to find a professional in your area.

Also, please visit the IETF website at www.legacy.vg/essentialtremor or call the office (toll free) at 888.387.3667 to learn more about planned giving options, how to name the IETF in your estate, and how to become a living member of our prestigious Legacy Society. ©



President's Club

Although every donation matters, regardless of size, those gifts of \$1,000 or more annually go a long way to further our mission. The IETF recognizes and thanks all those who donate at this level by including them in our **President's Club**. For more information about becoming a President's Club donor, call IETF Executive Director Catherine Rice (toll free) at 888.387.3667.

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Understanding Primary Writing Tremor

By Arif Dalvi, MD, MBA



Dr. Arif Dalvi

Primary writing tremor (PWT) is a type of task-specific tremor that occurs with handwriting. It has also been referred to as a “writer’s cramp” and is considered to be a focal dystonia or a variant of essential tremor, but may also be a distinct entity.

The diagnosis of tremor is based on clinical observation. Two main types of tremor are recognized. The first type of tremor occurs at rest, for example when the hands are resting in the lap. This rest tremor is sometimes referred to by the more picturesque names of “pill rolling tremor” or “money counting tremor” and is most commonly seen in Parkinson’s disease. The second type of tremor occurs during voluntary contraction of muscles (as opposed to at rest) and is called an action tremor. Action tremor can be of different types. The most common is a postural tremor, typically seen when holding

objects or holding the hands out in an outstretched posture. Such a tremor is seen in individuals who have essential tremor. Another type of action tremor occurs when a person is performing a specific task such as writing, drawing or playing a musical instrument and is called a task-specific tremor. The task that brings out the tremor is unique to each individual.

PWT is an example of a task-specific tremor that affects handwriting. Because other causes of tremor such as Parkinson’s disease and essential tremor can also affect handwriting, PWT is often misdiagnosed. The key differentiating point is that the specific task of writing is required to bring out the tremor. Other actions such as holding a cup of water, eating peas with a fork, or resting the hand in the lap will not elicit a primary writing tremor. Two types of PWT have been described. Type A or task-induced tremor occurs only while writing. Type B can occur even when the hand adopts a writing position and is called a position-specific tremor.

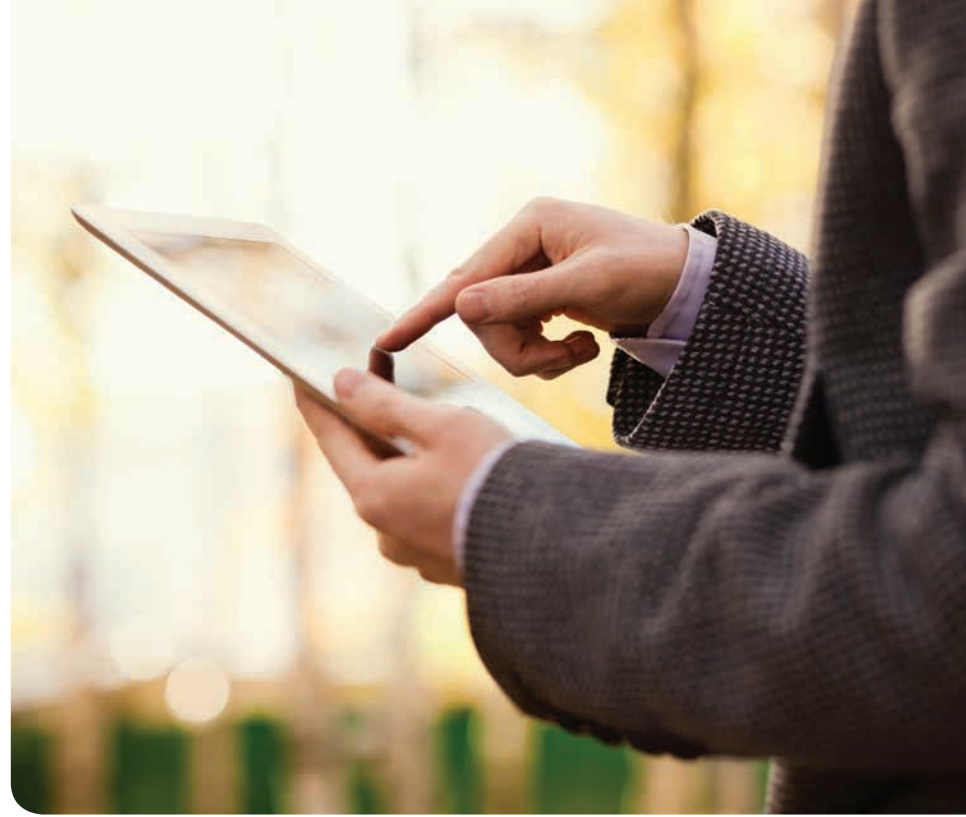
The cause of PWT is not well defined. A close relationship to dystonia has been postulated, with most cases considered a form of focal dystonia. Occupation may play a role in the development of PWT. A well-known case is that of Scott Adams, the artist behind the Dilbert cartoons. The artist almost gave up on his profession until he discovered that a change from pen and paper to a graphics tablet allowed him to continue drawing cartoons. Excessive use of the

hand for writing and drawing in such individuals may enlarge the cortical map or representation of the hand in the brain leading to dystonia and tremor. Using the graphics tablet is believed to be a form of sensory training, restoring the proper sensorimotor feedback loop in the brain. Other cases of PWT have features more typical of essential tremor, and a postural tremor more typical of essential tremor may be seen in such cases along with the tremor that occurs during writing. However, in contrast to essential tremor, the clinical presentation of PWT is more varied. Also the clinical response to alcohol is less common in PWT.

Treatment of PWT can include benzodiazepines (a class of drugs usually used for treating anxiety, panic attacks, depression, and insomnia) such as clonazepam. Medications that are also used to treat essential tremor such as propranolol and primidone generally are much less useful in PWT. Anticholinergic medications, medications that block the transmission of signals from one brain cell to another, have also been used with minimal success. Botulinum toxin injections provide the most benefit, although finding the right injection technique that reduces tremor without causing weakness in the hands can be difficult. There are occasional reports of deep brain stimulation (DBS) surgery being used for drug resistant PWT. However, the potential risks of DBS surgery, including brain hemorrhage, must be carefully balanced against the severity of disability in any given individual.

Orthotic devices can be helpful, as can using a thicker, heavier pen like the Poppin® pen, or following the example of Scott Adams, switching to a graphics tablet for those who have writing or drawing as a key skill in their occupation. 🕒

Dr. Arif Dalvi is the Director of the Movement Disorders Program Neuroscience Institute at Methodist Hospital in Merrillville, IN, serves as a Clinical Associate Professor of Neurology at the University of Chicago Pritzker School of Medicine in Glenview, IL, and is a member of the IETF Medical Advisory Board.



“Switching to a graphics tablet can be helpful for those who have writing or drawing as a key skill in their occupation.”

Tips and Tricks

- 🕒 Learn to use your tremor-free hand for as many activities as possible, including writing.
- 🕒 Use your tremor-free hand to steady your trembling hand and use two hands when possible.
- 🕒 Keep your elbows close to your body when performing tasks as a way to help control hand tremor.

Healthy Living for a Healthy Brain



For thousands of years people have searched for the secret of long life; the proverbial fountain of youth whose magical powers could return a person's youth and enable them to remain young and vibrant for eternity. Although there is no magic elixir that will turn back the hands of time, advancements in modern medicine are helping us all live longer, healthier lives.

It is estimated that one in 26 baby boomers is now expected to live to see their 100th birthday, and many more will reach their mid-to-late 90s. The latest U.S. Census Bureau data from 2010 shows that senior populations are increasing faster than younger populations, raising the nation's median age from 35.3 in 2000 to 37.2 in 2010, with seven states having a median age of 40 years or older¹. Although essential tremor can affect people at any age, the average age of onset is the mid-40s. So as our nation ages, the number of people affected by essential tremor may increase as well.

So in this modern age is there still hope for finding a fountain of youth? That depends. If you are looking for a magical pill that will make you 20 again, enable you to climb trees like a leopard and sprint like an antelope ... that probably isn't going to happen. But if you are looking for ways to live better and cope better with your tremor, then there may be some things you can do to help achieve your personal goals and keep your tremor in check.

Get Active

Americans spend an average of 34 hours a week watching television, and an additional three to six hours watching recorded programming. When looking at senior viewing habits, those 65 years and older, the number of hours spent watching TV skyrockets to an average of 48 hours a week, or nearly seven hours a day²! And these figures don't include all the additional hours spent surfing the Web and playing games.

We are a sedentary nation, and it is not good for our bodies or our brains.

Everyone knows that regular exercise is good for your body; it decreases the chance of heart disease, diabetes, hypertension and osteoporosis. But did you know that exercise may actually be good for your brain health and tremor as well? According to the Brain Institute at Oregon Health and Sciences University, our brains were built for movement equivalent to walking 12 miles every day. When you walk or swim or cycle, blood moves into your brain, bringing it glucose for energy and oxygen to soak up the toxic electrons that are left over. It also stimulates proteins that keep the neurons in your brain active and connecting. So if you want to improve your thinking skills and keep your brain healthy, you need to stay active.

Exercise affects the neurotransmitters that produce serotonin, dopamine and norepinephrine and possibly others. These chemicals influence our emotions, learning and focus³. Studies have also shown that a wide variety of exercises can help improve mood and alleviate some of the symptoms of depression. As depression and anxiety disorders affect many with essential tremor, exercise may be another way to combat unwanted symptoms of depression and keep tremor at its "normal" state.

There are literally thousands of exercise programs out there, and sometimes it can be difficult to know which is the best option for you. Although programs such as weight training, yoga and Tai Chi may be particularly beneficial for those with essential tremor, it is best to discuss your options with your doctor. It is important to make sure you pick activities that are appropriate for your physical abilities and current health conditions.



Physical activity will often increase tremor for a short period. It is completely normal. Give yourself a little extra time to cool down and your tremor will return to its normal state.

Stop smoking

According to the Centers for Disease Control and Prevention (CDC), tobacco use remains the single largest preventable cause of death and disease in the United States. Cigarette smoking kills more than 480,000 Americans each year, with more than 41,000 of these deaths from exposure to secondhand smoke. In addition, smoking-related illness in the United States costs more than \$289 billion a year, including at least \$133 billion in direct medical care for adults and \$156 billion in lost productivity⁴. Nicotine is a stimulant that may exacerbate tremor in some people.

The National Cancer Institute (NCI) offers help from trained smoking cessation counselors who can help you get ready to quit and answer your smoking-related questions in English or Spanish; (toll free) 1.877.44U.QUIT. You can also go online to www.Smokefree.gov for accurate, evidence-based information and professional assistance to help support your immediate and long-term needs as you try to quit smoking. Be sure to work with your doctor as well, to find a cessation program that will help you kick the habit for good.

Quit caffeine

Although caffeine consumption is not directly associated with the risk of developing essential tremor⁵ many find that caffeine exacerbates their tremor. It is best to avoid caffeine if you find that it makes your tremor worse. Common

sources of caffeine are coffee, tea, soft drinks and energy drinks, caffeine supplements, and (to a lesser extent) chocolate derived from cocoa beans. It is important to remember that “caffeine-free” coffees and teas still contain a small amount of caffeine, as it is a naturally occurring chemical present in the plants themselves and cannot be completely extracted. However, caffeine is an additive in soda, so caffeine-free soda really is caffeine free.

Eat better

The buzz lately is all about harmaline, a neurotoxin found in a number of foods we eat (especially cooked meat) that may be linked to tremor⁶. However, with 15 years of harmaline research under his belt as a lead researcher at Columbia University in New York, Dr. Elan Louis says, “The studies linking harmaline with ET are still underway and they are by no means definitive at this time. People with essential tremor should certainly not change their diet unless there is a clear and definite scientific reason to do so, and at the moment, the scientific studies are not complete.” Dr. Louis and his team are diligently pursuing their harmaline research and will continue to try to unravel the mysteries of what causes tremor and how the condition might be better diagnosed. Yet research in this area still has a long way to go, so don’t trade in your steak for a tofu just yet.

Continued page 8



“Everyone can agree that eating better is a good idea for all of us, at any age, with any condition.”

Continued from page 7

The effects of diet on some neurological conditions, such as Parkinson’s disease, have been thoroughly examined. But when it comes to the effects of diet on essential tremor, there are only a few small studies from which to glean information. Further study is needed in this area to truly understand its impact. However, eating more natural and healthy foods over fatty, processed foods is a good idea for a number of reasons. Fresh fruits and vegetables are packed full of essential nutrients that give you more energy, help reduce weight gain, and may even diminish the signs of aging. Even though more research in this area needs to be done for us to really understand how what we eat affects tremor, everyone can agree that eating better is a good idea for all of us, at any age, with any condition.

At this time there is no evidence to support that supplements and vitamins have any effect on essential tremor⁷. It is best to discuss your personal nutritional needs with your physician to ensure you are getting everything your body requires to function properly. Some nutritional deficits such as Vitamin B12 deficiency can cause tremor, although this type of tremor is not classified as essential tremor. If you think your tremor is caused by a nutritional need that is not being met through your regular diet, consult your doctor for appropriate testing, nutritional guidance, and an accurate diagnosis.

Don’t be fooled by supplements you find online that claim to be a cure for essential tremor. At this time there is no cure and no scientific evidence to support such a claim. Be aware that supplements do not have to go through the rigorous FDA (Food and Drug Administration) approval process and are not regulated. It is best to use your good judgment about these products and remember if it seems too good to be true, it probably is. However, if you do find something online that you are interested in trying, please consult your doctor first to be sure that none of the ingredients will react negatively with any of your current medications or health concerns.

Give back

Recent studies on the relationship between health and volunteering demonstrate that the benefits of volunteering are not limited to the recipients of the volunteer services. In fact, these studies show major health benefits derived from serving. When individuals volunteer, they not only help their community but also experience better health, in terms of greater longevity, higher functional ability, and/or lower rates of depression⁸. If you would like to help your community and yourself through

volunteering, consider becoming an IETF volunteer Support Group Leader. It will do both you and those you serve a lot of good! For more information, training materials, and an application for volunteer service visit www.essentialtremor.org/volunteer.

The secrets to long life are not found in some mysterious, magical elixir or even the latest supplement or greatest gadget. The real secret is so much simpler:

- **Celebrate life** every day and do your best to stay positive.
- Practice **healthy habits** and eat lots of whole foods, fruits and veggies.
- Take time to relax and **do the things you love**, even if it's hard.
- Stay active and **participate in life**.
- **Find purpose** through volunteering and giving back.
- Remember that millions of people are affected by ET and **you are not alone.** ©

Resources:

¹ Howden, Lindsay M., and Meyer, Julie A. Age and Sex Composition: 2010 Census Briefs. <http://www.census.gov/prod/cen2010/briefs/c2010br-03.pdf>, May 2011.

² Hinckley, David. Americans spend 34 hours a week watching TV. New York Daily News, <http://www.nydailynews.com/entertainment/tv-movies/americans-spend-34-hours-week-watching-tv-nielsen-numbers-article-1.1162285#ixzz35r24SElz>, September 19, 2012.

³ Northridge, Kathleen. Exercise & Brain Neurotransmitters. <http://www.livestrong.com/article/96493-exercise-brain-neurotransmitters>, August 16, 2013.

⁴ U.S. Department of Health and Human Services. The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2014.

⁵ Louis, E. D., Jurewicz, E. C., Applegate, L., Luchsinger, J. A., Factor-Litvak, P. and Parides, M. Semi-quantitative study of current coffee, caffeine, and ethanol intake in essential tremor cases and controls. *Mov. Disord.*, 2004; 19: 499–504. DOI: 10.1002/mds.20035.

⁶ Louis E.D., Keating G.A., Bogen K.T., Rios E., Pellegrino K.M., and Factor-Litvak P. Dietary Epidemiology of Essential Tremor: Meat Consumption and Meat Cooking Practices. *Neuroepidemiology*, 2008; 30:161–166. DOI: 10.1159/000122333.

⁷ Louis, E. D., Jurewicz E. C., and Parides M. K. Case-control study of nutritional antioxidant intake in essential tremor. *Neuroepidemiology*, 2005;24(4): 203-8. Epub 2005 March 30.

⁸ Brown, S., Nesse, R. M., Vonokur, A. D., & Smith, D. M. (2003). Providing Social Support May Be More Beneficial Than Receiving It: Results from a Prospective Study of Mortality. *Psychological Science*, 14(4): 320–327.

Band-Aid of the Future

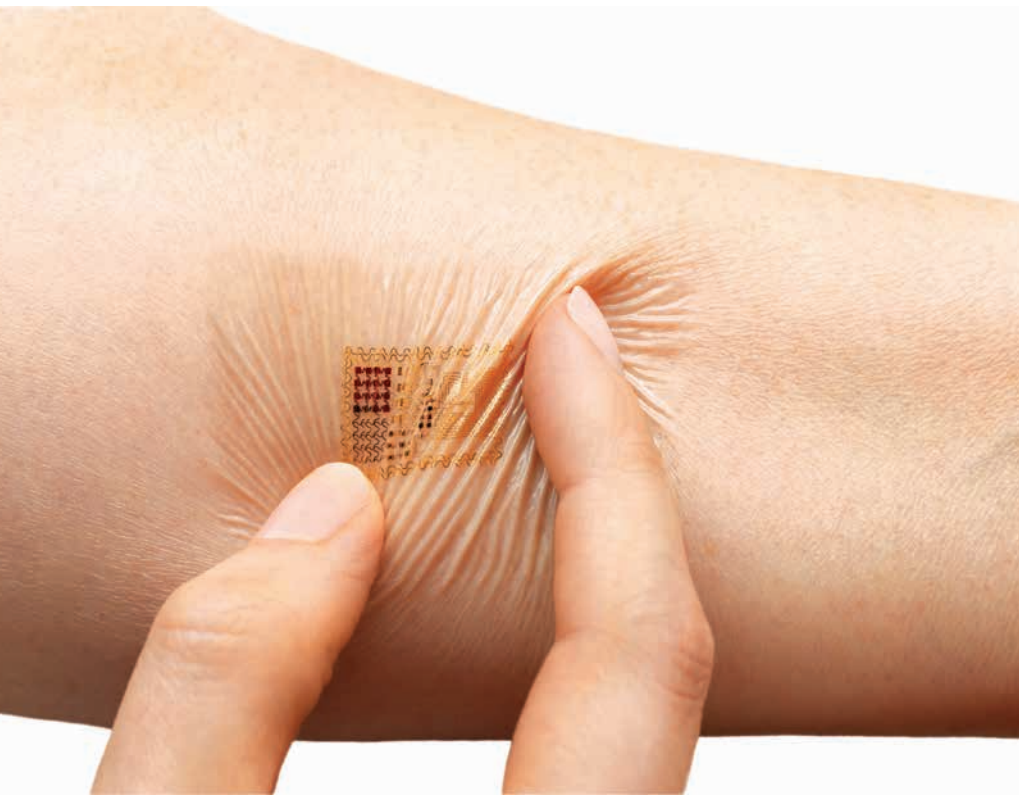


Photo credit: MC10, Inc.

Imagine a future where technology could go even further, and even smaller. Imagine technology so sophisticated and microscopic that it allows you to “wear” your ET medication like a Band-Aid. What if that same flexible, ultra-thin Band-Aid-like device could record your tremor amplitude as your medication is delivered, and then digitally send your health data directly to your physician?

Your physician could review how the medication is affecting your muscle contractions, heart rate, blood pressure, temperature, respiration and more. Seems more like something straight out of Star Trek; too far-fetched and fanciful even for today’s advancements, right?

Well, in a word, no! This future is not as far-fetched as it may seem. Nanotechnology is advancing diagnostic tools to create new medical devices that could impact the lives of millions. “The [technology] represents a new direction in personalized health care that will eventually advance diagnostics and therapy on devices that can be worn like a child’s temporary tattoo,” explained Dae-Hyeong Kim, assistant professor of chemical and biological engineering at Seoul National University, to David Talbot of the MIT Technology Review.

MC10, a start-up company in Cambridge, MA, is developing soft, stretchable and “wearable” technology. Tiny microsensors are combined with stretchable metallic connections and are powered by a rechargeable ultra-thin battery. Personal health data is stored inside the patch, in memory cells that are just 30 nanometers thick, or equal to the width of a particle of cooking oil smoke. Health data can then be digitally sent to the treating physician using wireless Bluetooth technology, so that the physician

Technology is moving faster and faster every day. Yet the size of technology is getting smaller and smaller. There was a time, not so long ago, when a mobile phone was a heavy, clunky box with a wired receiver that you lugged around on your shoulder and hoped it actually worked if you should ever need it. Today, advancements in nanotechnology (the manipulation of matter at an atomic, molecular, and supramolecular scale) have given way to light weight, super-thin devices that can not only be used as a phone, but also as a camera, personal computer and game system. **And it all fits easily into your pocket.**



Photo credit: MC10, Inc.

MC10 has also created an easy-to-apply patch that continuously monitors and wirelessly transmits a child's temperature to the parent's smartphone, allowing new parents to forgo the standard ways to check their child's temperature. It's a much more comfortable process for parents and baby.

can review vital information and personalize treatment options accordingly.

Imagine not having to remember to take your meds every day, but just to slap a patch on your arm. The patch would release the appropriate dosage of medication as prescribed by your doctor and your body's reaction to the drug would be recorded. When evaluated by the doctor, there would be no more question of whether or not prescribed treatments are working; the data would better determine the effectiveness of the therapy.

Currently MC10 is working on utilizing this technology in sports & fitness, consumer health and regulated medical devices. They have already launched a sports related product in partnership with Reebok. The Reebok & MC10 CHECKLIGHT™ is a skullcap that can be worn underneath an athlete's helmet that indicates with flashing LED lights whether the athlete needs to be assessed after sustaining a blow to the head. MC10 is also investigating how this technology might be used to monitor the heart

rate and temperature of babies, without the need for uncomfortable lead wires and bulky machinery.

This is the future of diagnostics and treatments. Major advancements in technology allow for devices that are more and more sophisticated and, at least in this case, more patient centered.

Some of the top minds in the engineering, programming, and nanotechnology are working diligently to find solutions to real world medical problems. And one day, in the not so distant future, this type of technology will be as commonplace as cell phones and touch screens are today.

To learn more about this technology, including the Reebok & MC10 CHECKLIGHT™, visit the MC10 website at www.mc10inc.com. ©

By Brett Wiscons



MY NEW NORMAL

Photo credit: Kurtis Bowersock

Not all coping skills are positive. Sometimes, in our effort to minimize stress and/or conflict, we employ strategies that actually make things worse. Those affected by essential tremor have options when it comes to their tremor: They can either choose to be open about their shaking or attempt to hide it. Brett Wiscons spent many years hiding his essential tremor. As a musician and author, he felt it was just too hard, too embarrassing, too not-normal, to reveal. But what he didn't expect was that hiding who he really was would add so much unnecessary fear and anxiety to his life. Just recently he began to talk openly about his ET. This is his story ...

I first remember my tremor rearing its ugly head back in high school. Fitting in at that age was hard enough, but having shaky hands made it so much worse. I remember sitting in the cafeteria with my friends trying to remove the tightly-wrapped foil from around a baked potato. I tried to peel back the foil quickly so that no one would notice my struggles, but my hand shook so violently that little silver bits were propelled across the table. Some of my friends laughed and poked fun as the bits flew by. They chuckled and I even joked about it with them. But for me, on the inside, it wasn't funny at all.

Because my parents didn't make a lot of money, I was already dealing with the shame of receiving free school lunches and the looks associated with that. So this tremor was just one more thing that made me feel different from everyone else when all I wanted was to just be normal.

Growing up in Indiana, I dreamed of being a professional musician. I would escape to my room, turn on some Hootie & the Blowfish, close my eyes and dream about singing "Only Wanna Be with You" to a packed arena filled with gobs of adoring fans. I wasn't sure exactly how to get there, but I knew I wanted that job.

But it was hard. I was so self-conscious about my shaky hand that I made it a point to try to keep my essential tremor hidden from the rest of the world. And for a while, it seemed to work. I made it through high school and college without my tremor really getting in my way too much. I played sports, dated girls, and otherwise lived my "normal" life.

"I used to be afraid that someone might see my shaking ... and then everyone would know I was different"

When it did get in the way though, it was terrible. I tried to teach myself how to play guitar, but my tremor made it seem impossible. My left hand and thumb refused to glide naturally across the fret board like Mark Bryan (lead guitarist for Hootie). I lacked his grace and effortless motion. I got antsy, impatient and frustrated. I just didn't know how to deal with it.

I tried to hide my condition, but it was always there. I used to be afraid that someone might see my shaking and say something to one person, who might tell someone else, who would tell someone else, and then everyone would know my secret. Everyone would know I was different, not normal. For so long, this was a very real and very frightening thought to me.

That could be why I decided to try my luck as a lead singer instead of a lead guitarist. Although I would be

front and center, my hands wouldn't. I sang with a few bands and even managed to play a little guitar here and there. It was nice to have a band behind me. Knowing I was not alone helped me focus and keep my tremor in check. Over the years, with practice and repetition, playing in front of audiences has gotten much easier. I am not as focused on my tremor and whether people are noticing it. But there is still that little bit of anxiety for some of my bigger performances, and of course, the tremor is always there. I know it always will be.

Just this past December, I was asked to sing the national anthem prior to an NBA basketball game in front of 20,000 people. To be honest, if they said I had to accompany myself on guitar, I would have turned it down. I was worried that the sheer magnitude of the performance would exacerbate my tremor so badly that I wouldn't be able to play at all. So I did what so many of us do; I found a work-around. I suggested that I sing it a capella and (thankfully) they agreed. The audience loved it! That was a real turning point.

Over the years, I think I've done a pretty good job of hiding my tremor. I used to think that was a good thing, something to be proud of. However, as I begin to play more and more solo acoustic shows, I have become more accepting of my tremor. When it's just me and my guitar under the spotlight I can't conceal my hands under a table or bury them in my pockets.

And besides, I don't want to hide it anymore; I don't want to be ashamed or afraid anymore.

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Photo credit: Kurtis Bowersock

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I am proud to say **this is my NEW normal.**

I know how tough it can be to use a soup spoon or button a shirt. I struggle with these seemingly easy, day-to-day tasks too. But I think it shows your true character to keep soldiering on and finding a way, day after day, to keep rising above the challenges.

I want to be an inspiration to others. My career is slowly building. I've released a new album, which was produced by a two-time Grammy Award winner, debuted a new music video, and even published my second private detective novel. And while I don't expect to be famous around the globe, I have started to gain fans across the U.S. I want to use this public platform to help raise awareness and find a cure for this life-altering condition. As my career grows, I know I can make a difference. Maybe I can help reach the next generation and be an example that anything can be done if you set your mind to it, even having a career in the entertainment and music industry, even with essential tremor.

I have learned several things that help keep my tremor under control. I do yoga regularly to help strengthen my core and help my overall flexibility. It also helps me relax and relieves a lot of my day-to-day stress. I eat small meals more frequently and get plenty of sleep (when I don't have a late night gig). I avoid anything with caffeine, as it seems to make my tremor worse. I also take a beta-blocker when I need a little extra help.

It has taken me a while to get to the place I am now, in my career and in life. I realize now that most people never get the opportunity to do what they love for any amount of time. I consider myself to be very lucky that I have been able to do this for so long. And although I worry about what the future may bring, I don't let negative thoughts consume me. I know that someday I may have to hang up my guitar and put down the mic for good, but that day is not now. Now is the time to enjoy the ride. And enjoy it I will!

Essential tremor is just something I have. It is my new normal. I know that now. If you feel beaten down or worry that you can't achieve your dreams, I hope you'll look at my story for inspiration. Having ET doesn't have to define you. There is no shame in having it. I encourage you to follow your dreams. Tell yourself you can and then get out there and do it. And keep doing it, trying, over and over until it happens for you. Grab that air guitar and follow your dreams, no matter if you're eight or 80. **Make it YOUR new normal.** ©

You can learn more about Brett, his music and books, at his website, www.brettwiscons.com or email Brett at booking@brettwiscons.com.

Ask the Doctors

Q.

I read an article about someone whose tremor stopped after application of nicotine patches. Although the person in the article had Parkinson's disease, would it be helpful for essential tremor too?

A.

Nicotine in pre-clinical studies has been shown to protect dopaminergic neurons from dying. It is the loss of dopaminergic neurons over time that is the underlying cause for Parkinson's disease. Because this is not the underlying cause of ET, nicotine patches would not be expected to help with ET. Even if there was evidence that it could work for ET, it is hard to use the example of one person and apply it to others. There is a well known placebo effect from therapeutic interventions, which is why we study drugs and other agents in clinical trials.

Kelvin L. Chou, MD

Thomas H. and Susan C. Brown Early Career Professor, Associate Professor, Neurology and Neurosurgery, Co-Director, STIM (Surgical Therapies Improving Movement) Program at the University of Michigan Department of Neurology, and IETF Medical Advisory Board Member

Q.

I understand that children can also have ET. Is it normal for little kids to have shuddering spells as part of their essential tremor?

A.

In a small study of six infants and children presenting with shuddering attacks, there was evidence and a family history of essential tremor. Although this association had not been previously recognized, the shuddering spells caused considerable concern and led to a wide range of diagnoses. The shuddering attacks start in infancy or early childhood. They are brief, often associated with some posturing, and may be very frequent. They are benign and tend to become less frequent or stop completely by age ten. The recognition of this syndrome could avoid unnecessary investigation and concern. The function of shuddering attacks seems to represent an expression of the mechanism of essential tremor in the immature brain. The ultimate nature of these attacks will undoubtedly be clarified when a neurochemical basis for essential tremor is found.

Arif Herekar, MD

Medical Director, Neuro Diagnostic Centre at Hamdard University Hospital in Karachi, Pakistan, and IETF Medical Advisory Board Member

We invite you to send in your ET questions to info@essentialtremor.org or call us (toll free) at 888.387.3667. Your question may be featured in the next issue of *Tremor Talk* "Ask the Doctors".

Fall 2014 IETF Scholarship Awards

Each semester, the IETF awards \$500 scholarships to qualified post-high school students of all ages, to lessen the burden of higher education. These scholarships can be used for supplies, books or tuition at licensed, accredited institutions of higher education (including trade schools) and are paid directly to the educational institution.

On behalf of the IETF staff and Board of Directors we offer our congratulations to these amazing students. We know their passion and dedication will take them far.



Alyssa Mendelsohn

Alyssa is an incoming freshman at Ithaca College in New York. She overcomes her challenges with ET by keeping a positive outlook. “Living with tremor is all I know,” said Alyssa. “In that sense, I’m lucky. I grew up knowing I’d never be a brain surgeon. Nothing’s been taken from me. I don’t feel cheated. Shaking is as second nature to me as blinking.”

Alyssa has been a synchronized ice skater for six years and serves as team captain of her national award-winning team. She also volunteers for Give Kids the World and as a coach for a young, beginning ice skating team. During high school, she was active in choir and founded Jam Sesh, a club where students can go to let off steam and share their passion for music.

“Having ET hasn’t been easy. But it’s been my journey. And I wouldn’t trade it for anything,” said Alyssa. “I have essential tremor. And I’m only getting started – shaking things up.”



Kaleigh Knapp

Currently pursuing a Communication Studies degree at the University of North Carolina at Chapel Hill, this is Kaleigh’s second IETF scholarship. Kaleigh understands the challenges of living with ET through her own experiences and by watching her mother, who also has ET. “My mom’s positive outlook on living with essential tremor gives hope to those struggling with their diagnosis, teaching all of us that nothing should keep us from living our dreams,” said Kaleigh.

Kaleigh uses her daily struggles with having ET by motivating others as an active community leader. She volunteers for Hospice and Palliative Care of Cabarrus County and Orange County Rape Crisis Center, and is a member of Phi Beta Chi Sorority and the Pitts Baptists Church College Youth Group.

“I have never seen essential tremor as a disability, yet that is how it is seen in the eyes of other people. I see it as something that makes me unique,” Kaleigh said.



Paul Schoolman

As an incoming freshman to McDaniel College in Westminster, MD, Paul understands the challenges of living with ET. “Having essential tremor has been a major inconvenience, at times an embarrassment and very frustrating, but nothing I cannot overcome,” explained Paul.

During high school, Paul excelled in and outside the classroom. He was an AP scholar, member of the Student Government Association and National Honor Society and named Century High School Valiant Knight, the school’s prestigious honor of peer facilitator. Paul also volunteered as a Hashawha Outdoor School camp counselor and traveled on a study tour to Costa Rica.

“His consideration and compassion for others, along with his determination have helped make him a student leader,” said Randy J. Clark, principal of Century High School. “As a student he has helped our school to excel. I am sure that he will continue to do well in the future with this type of attitude.”



Jared Beeson

The IETF is pleased to award a scholarship, sponsored by The Goulden Touch Foundation, to Jared Beeson of Oconee, IL. The Goulden Touch Foundation was founded by All Pro Kicker Robbie Gould with a mission to help those in need in the areas of: health and wellness, medical research, social service and education. The mission of this scholarship is to help students in Illinois affected by essential tremor.

As an engineering major at Eastern Illinois University, Jared serves as an inspiration to all students living with ET. “I believe that we become stronger when we are forced to face difficult situations.” Jared said, “I have learned to cope and adapt to the challenges in my life. I believe ET has made me a stronger person and instilled a sense of compassion and empathy for those going through difficult situations.”

During high school, he was a standout football and varsity track star, a member of the Illinois All-State Academic Team and National Honor Society and served as a personal aide to a fellow high school student with cerebral palsy during the summer months. Beeson channels the daily challenges of his ET to push for success as an academic scholar and natural leader.

“I know that whatever job Jared is given, he gives it his best,” said Rev. Allen J. Ebbler, Jared’s pastor and coach. “Whether working for pay or a pat on the back, Jared gives 100 percent of himself to any task he is given.”

“I think it’s awesome that I received a scholarship from Robbie Gould because I have been a lifelong Chicago Bears fan,” Jared explained. “I am grateful to the Goulden Touch Foundation to be the recipient of this scholarship.”

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Sarah Kunz

Currently pursuing a degree in American Sign Language Interpreting (ASLI) at St. Catherine University in St. Paul, MN, Sarah uses her ET as motivation to help others who are struggling with daily challenges. “I have a diagnosis of ET; it’s not a disability. It may be a challenge sometimes, but it empowered me to achieve my dream: I dream of helping the Deaf achieve their dreams,” Sarah explained.

Sarah succeeds as an academic scholar and an active leader within her community. She currently serves as a teaching assistant for ASLI at the University of Minnesota, volunteers for Love INC Big Woods and recently traveled to Ghana, Africa and East Asia as part of the missionary program for Cru (formerly Campus Crusade for Christ). “Not even essential tremor can stop my dream,” said Sarah. ☺

Focused Ultrasound Thalamotomy Study Needs Volunteers

Thalamotomy is a surgical procedure for essential tremor that has been used since the 1950s. Prior to FDA approval of deep brain stimulation (DBS) surgery in 1997, thalamotomy was really the only surgical option available for those who had severe ET and were not helped by available medications. In this procedure, beams of ionizing radiation come together at a single point deep within the brain. As individual waves of energy, the radiation passes through tissue and bone without damaging it. However, when these waves converge on a single point, it burns away a small section of tissue; in this case, tissue in the thalamus (the part of the brain that coordinates movement, the senses, and consciousness). The lesion is only a few millimeters in diameter, but it is enough to disrupt the signals being sent from the brain that tell a hand to tremor.

Researchers around the world are currently working on the next generation of thalamotomy called focused ultrasound. Focused ultrasound is a form of thalamotomy that may be a

surgical option in the future. Studies are being conducted at several sites around the world, to test the effectiveness of this procedure and its safety.

Focused ultrasound is performed while the patient is awake and involves no anesthesia, no incisions in the scalp, and no holes through the skull. During focused ultrasound surgery, cells in the thalamus are viewed by the surgeon in real time using a Magnetic Resonance Imaging (MRI) scan. Focused beams of acoustic energy then converge to heat and destroy the targeted cells without damaging any of the surrounding brain tissue.

Focused ultrasound is in the third phase of study, and participants who are affected by essential tremor are needed as volunteers. If you are interested in learning more about the procedure you can visit the Focused Ultrasound Foundation website at www.fusfoundation.org. ☺

If you or a loved one are interested in participating in the focused ultrasound study, contact the study site nearest you:

University of Maryland Medical System

Baltimore, MD, United States
Contact: Andrea Reddick | 410-328-4723
Principal Investigator: Howard Eisenberg, MD

Stanford University Medical Center

Stanford, CA, United States
Contact: Ricardo Valenzuela | ricardov@stanford.edu
Principal Investigator: Pejman Ghanouni, MD

Sunnybrook Health Sciences Centre

Toronto, ON, Canada
Contact: Maheleth Llinas | 416-603-5800 ext. 6121 or
Maheleth.Llinas@uhnresearch.ca
Principal Investigator: Michael Schwartz, MD

Swedish Medical Center

Seattle, WA, United States
Contact: Amanda Brown | 206.320.3070
Principal Investigator: Ryder Gwinn, MD

Tokyo Women's Medical University (TWMU)

Tokyo, Japan
Contact: Miyoko Naganuma | +81 (0)3-5269-7386 or
naganuma.miyoko@twmu.ac.jp
Principal Investigator: Takaomi Taira, MD, PhD

University of Virginia

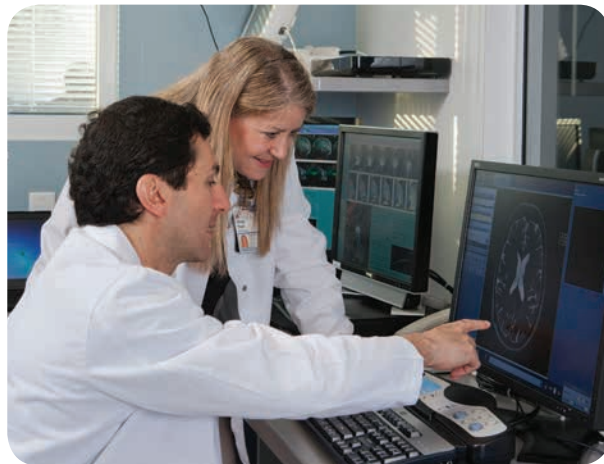
Charlottesville, VA, United States
Patient inquiries can be directed to the UVA Neurosurgery Clinical Trials division.
Contact: Johanna Loomba | 434.243.1435 or
FUSbrain@virginia.edu
Principal Investigator: Jeff Elias, MD
Due to the high volume of inquiries email is recommended.

Yonsei University Medical Center

Seoul, Korea
Contact: Eun Jung Kweon | kweonej@yuhs.ac
Principal Investigator: Jin Woo Chang, MD, PhD



Dr. Michael Schwartz of Sunnybrook Health Sciences Centre in Toronto speaks with a patient during an MRI-guided focused ultrasound procedure. Photo Credit: Sunnybrook Health Sciences Centre.



Dr. Jeff Elias and his team at the University of Virginia use focused ultrasound to treat ET as part of this clinical trial. The focused ultrasound is controlled using a computer in the adjacent room where MRI scans are used to pinpoint the target area. Photo Credit: University of Virginia.



IETF FUNDS ET RESEARCH

Each year researchers with an interest in studying the various aspects of essential tremor are encouraged to submit scientific proposals for grant funding from the IETF. To date, your research donations have provided more than \$750,000 to fund 30 promising studies.

Below you will find the three studies that were selected to receive this year's IETF research grants. Please take some time to review these promising studies to better understand the work currently going on in the field of ET research.

The Role of Excitotoxicity in Essential Tremor Cerebellum

The cause and development of ET remains poorly understood. Functional imaging studies show cerebellar abnormalities in patients living with ET. The goal of this research is to investigate the role of excitotoxicity in the postmortem essential tremor cerebellum. Excitotoxicity is the pathological process by which nerve cells are damaged and killed by excessive stimulation by neurotransmitters. It has been a suggested approach for ET, however there has yet to be any direct evidence that excitotoxicity plays a role in ET patients.

Researchers propose to test this hypothesis by examining the number of excitatory synapses (structures that permit a neuron to pass an electrical or chemical signal to another cell) and the levels of excitotoxicity markers in the ET cerebellum. This will be the key step to understanding the process of cerebellar degenerative process in ET. The study will be conducted by Dr. Sheng-Han Kuo at the Essential Tremor

Centralized Brain Repository, New York Brain Bank, Columbia University, New York.


Cerebello-Thalamo-Cortical Coupling in ET

Although the cause and development of ET is not fully explained, tremor is associated with abnormal activity within different brain regions, particularly the thalamus and cerebellum. Deep brain stimulation (DBS) reverses symptoms of tremor but is an invasive procedure. Transcranial stimulation of the cerebellum may represent a non-invasive therapeutic option for ET patients. Transcranial stimulation (tACS) is a new technique allowing manipulation of rhythmic patterns in the brain's cortex with externally applied electrical frequencies. Researchers propose to test the effectiveness of cerebellar stimulation in ET patients previously operated for DBS. To further understand how this treatment provokes tremor reduction, they will analyze the brain neuronal activity in other ET patients who are candidates for DBS by using electric current recordings of the thalamus, cerebellum and cortex. The study will be conducted by Dr. Marie-Laure Welter at Groupe Hospitalier Pitié -Salpêtrière in Paris.

ET Brain Bank at the Arizona Study of Aging and Neurodegenerative Disorders

Now in its third IETF-funded year, researchers will continue to examine the brain tissue of those with ET and other neurological disorders after death, searching for a greater understanding of how ET changes the features of

the brain, and hopefully leading to more effective diagnostic tools. They will also compare the clinical findings of early onset ET and ET beginning after age 65. They will then also clinically categorize action tremor in the elderly and serially assess tremor and non-motor signs. Researchers will examine all brain areas using previous standardized assessments with the goal to explore whether there are any brain regions that may have been overlooked in smaller surveys in the past. This study will be conducted by Dr. Holly Shill and Dr. Charles Adler at Banner Sun Health Research Institute in Tucson, AZ.

Right now we are working to raise enough money to fund next year's research grants. Your research donation could make the difference between critical research being funded or being turned away. **Every donation, no matter the size, counts.** Please help us keep research moving forward by making a research donation today! Call (toll free) 888.387.3667 to donate over the phone, mail a check to the IETF (PO Box 14005, Lenexa, KS 66214) or save a stamp and make your research donation online at the IETF website, www.essentialtremor.org/ways-to-give. 

Moving FORWARD

RESEARCH & HOPE FOR ESSENTIAL TREMOR

With every research project funded, our understanding of essential tremor moves forward. The road to better treatments and ultimately a cure, could be just around the corner.



To learn more about how your donations support essential tremor research, please visit our website at www.essentialtremor.org/research.



Raise Your Voice for Change



Unlock the mysteries of the brain and advocate for research through the Congressional Neuroscience Caucus. It is only through scientific research that the causes, prevention and ultimately cure of neurological disorders, like ET, will be found.

What the Neuroscience Caucus does:

- Sponsors briefings on research and findings
- Collaborates with research organizations to build awareness
- Distributes congressional information
- Promotes legislation to advance neuroscience research



What you can do:

Reach out to your U.S. Representative and ask them to support the Neuroscience Caucus today. Find your Representative at www.house.gov/representatives. ☺

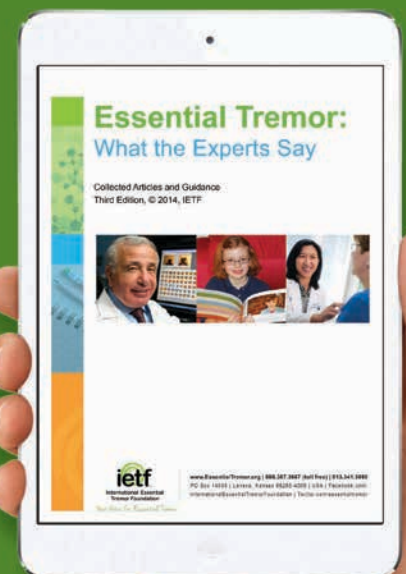
E-book for Annual Donors Essential Tremor: What the Experts Say

By donating just \$30 you'll receive the IETF's new e-book, *Essential Tremor: What the Experts Say*. This 198-page e-book is a collection of more than 80 articles authored by the world's finest movement disorders specialists and experts. It's an invaluable reference book with extensive information on the many different aspects of ET.

This new book is compatible with any e-Reader or you can download it in PDF format to your computer.

As an annual donor to the IETF, you'll also receive the latest information in our monthly *Tremor Gram* e-mail and receive a one year subscription (three issues) of *Tremor Talk* magazine.

Make your annual donation today at www.essentialtremor.org/donate. ☺



Something Souper from Lift Labs

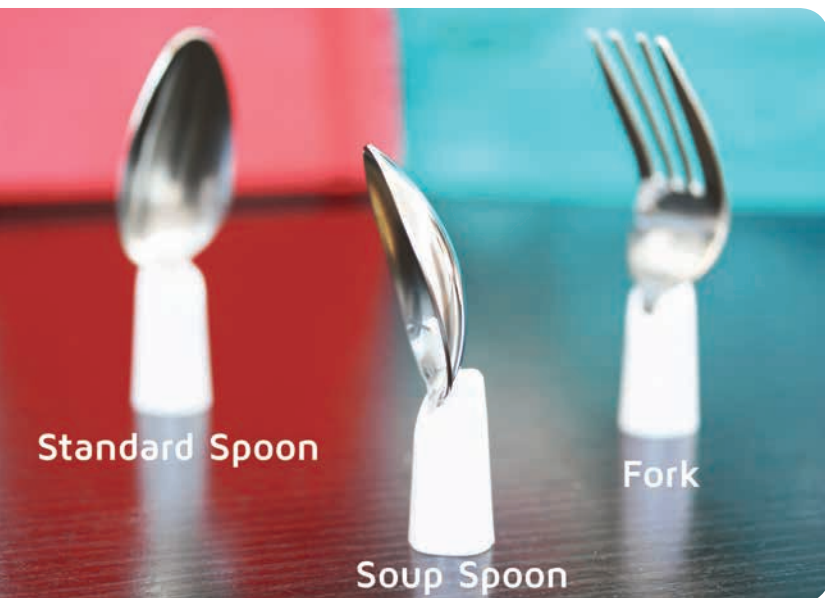


Photo credit: Lift Labs

Lift Labs, the makers of Liftware, have introduced some new attachments for their innovative tremor canceling spoon. New fork and soup spoon attachments fit easily onto the stabilizing handle (sold separately) and are available for just \$19.95 each.

The new soup spoon is deeper and wider than the standard spoon attachment that comes with the system, and holds about 15 ml (one tablespoon) of liquid. This is a great attachment for soups, cereals, and other liquids. The fork attachment has a deep-scooped profile to hold more food and makes enjoying pasta and salads possible again.

What makes this technology so unique are the sophisticated sensors in the stabilizing handle of the spoon. It detects and counters tremor; quickly responding to tremor movements and steadying whatever you are holding. Many people with essential tremor have found this product very helpful as it responds well to the rhythmic shake of ET. However, this system does not seem to work as well with dystonic tremor conditions, or tremor that is very jerky in nature. Thankfully there is a 30-day money back guarantee if you are not satisfied with the system.

The Liftware system includes a stabilizing handle, standard spoon attachment, storage case, handy travel bag, and charging station. The system is priced at \$295 and ships free within the United States.

If you are unable to afford a Liftware system and have essential tremor, Lift Labs has a donation program available. If you would like to be considered to receive a donated system, please download and complete the IETF's online application at www.essentialtremor.org/treatments/assistive-devices. To be considered, you must complete and submit the application, provide a letter from your treating physician confirming you are affected by ET, and submit a copy of the first page of your tax return, showing gross and net income. Donations are given based on need and are available on a first come, first served basis.

Please note that the IETF does not pay for Liftware nor does it solicit donations to pay for the Liftware system. The IETF does not sell Liftware in our webstore. The IETF simply assists Lift Labs in making sure that the donated Liftware systems are distributed to those in need.

For more information, helpful product videos, or to place an order, contact Lift Labs at www.liftlabsdesign.com or call 415.894.LIFT. ©



Photo credit: Lift Labs



Honoraria and Memorials

Thank you to everyone who established memorials and contributed funds to honor loved ones on behalf of the IETF from March 15, 2014 to July 14, 2014. If your donation was processed after July 14, 2014, it will be listed in the next issue of *Tremor Talk*. (Honoraria or Memorials are listed in UPPERCASE, donors are listed in *italics*.)

HONORARIUMS

CELE & SID AWERBUCK
Ryan Weiss

KOBY BEN-EZRA
Jerry & Dale Rubin

LILLIAN COURTHEOUX
Richard & Perri Courtheoux

MR. & MRS. RICHARD
COURTHEOUX
Lillian A. Courtheoux

CATHY SLAVIK'S CHILDREN'S
MARRIAGE
Shari & Stan Finsilver

THELMA WACKS
Linda Kaplan

MARY GRANDIA
*Dennis & Marcia Albertson
Donald & Deborah Grandia
Kenneth & Kathy Grandia
Health Catalyst
Kyle & Haley Lieber
Thomas & Carol Mclean
Genevieve Smith
Estate of Mary Grandia*

DOROTHY GROLL
*Erma Biler
Ruth Groll
William & Virginia Martini
John & Cathy Pfeil
Otis & Lois Sonnenberg
Michael & Sharon Tackaberry*

MARIAN HENDERSON
Laura W. Stiles

VIRGINIA HOFFMAN
Barry & Susan Roberts

LOIS HOWARD
Charles Damsel & Family

JAMES HYLER
Anita Farrell

ARLINE JELLINEK
Elaine Levin

JOYCE KAISER
Stephen & Barbara Kaiser

ROBERT KLEIN
JoAnn Klein

BRUCE KORT
Harold Kort

WILMA KRUEGER
Ivy Girocco

R. LUCK
Carol S. Luck

JAMES MATTHEWS
Judy Knutson

JOAN MEANY
*Erin Conley
Helen Didriksen*

LOUIS OTTO
Carol L. Moody

SUSAN PAULES
Charles E. Paules

JULIA PETTIGREW
Murial Kessler

CHARLES RANSELL
*Cincinnati-Dayton ET
Support Group*

JAMES RICHARDSON
Dr. & Mrs. Howard McQuillen

DONNA RICKER
*Jayne Berry-Steel
Kevin & Stacey Donase
Dr. Leslie Gordon
Gretchen Morin*

VIRGIL V. SABOURIN, SR.
Joanne H. Morse

INEZ SCHLEICH
Cheryl Gilmore

EVELYN SHAW
James Shaw

KENNETH SMITH
Ronald & Carol Jerome

MEMORIALS

MRS. DICK BERGGREN
North Shore ET Support Group

JOHN BERNARD
*Deborah Fleagle
Gilbert Herman
Charles & Connie Walt*

RON & PAT COWAN'S BROTHER
Shari & Stan Finsilver

AUDREY DAHLGREN
*Gordon E. Dahlgren
Philip & Mary Jo Dyer*

ROBERT GILBERT
Ron & Carol Jerome

Free ET Seminars

The IETF facilitates 20 to 25 educational seminars each year in order to educate patients, healthcare providers and the general public about essential tremor. These seminars cover several topics including the diagnosis process, current treatment options, research, occupational therapy, assistive devices, and more.

Is an IETF Seminar Right For You? If you answer “yes” to any of the following questions, an IETF educational seminar might be the right opportunity for you to learn more about essential tremor and become a better advocate for your own health:

1. Do you know what type of doctor to see about your shaking hands, head and/or voice?
2. Do you know how essential tremor is diagnosed?
3. Are you aware of both the medication and surgical options for essential tremor treatment?
4. Would you like to learn more about current ET research?
5. Are you interested in assistive devices that may help with every day activities?
6. Would you like to be in a room full of people who truly understand what you are going through; where no one will ask if you are cold or nervous?

Here are some of the cities we will be visiting this fall. Be sure to check the IETF website at www.essentialtremor.org/seminars for specific dates and times and to RSVP.

Raleigh, NC	Phoenix, AZ
Fresno, CA	Philadelphia, PA
San Francisco/San Jose, CA	Danville, PA
Minneapolis, MN	Boston, MA
Tulsa, OK	Long Island, NY
Fort Worth, TX	Concord/Lebanon, NH
Memphis, TN	Fort Wayne, IN
Atlanta, GA	Orlando, FL
Nashville, TN	Viera, FL
Albuquerque, NM	

MARJORIE STEIN
Barry & Susan Roberts

JENO SZAMOSVARI
Renate A. Ritter

NORMAN USTLER
Charles H. Damsel & Family

EUGENE WEAVER
Marilyn Weaver

MURRAY WEISS
Barbara Morris

LEE WOOD
Ruth Darling

Celebrate birthdays, anniversaries or special occasions with a gift “in honor of” family and friends. Or remember loved ones who have passed on with a gift in honor of their memory. Making an honorarium or memorial donation is a great way to recognize those close to you, while supporting the mission of the IETF.

You can make your donation online at www.essentialtremor.org/ways-to-give or by calling the IETF office (toll free) at 888.387.3667.

IETF on the Move!



Catherine Rice, IETF Executive Director and Tom Bruderle, IETF DC Liaison, conducted a series of visits to Congressional staff in conjunction with a Capitol Hill presentation by the bipartisan Congressional Neuroscience Caucus, sponsored by the American Brain Coalition. Tom and Catherine both attended the Neuroscience Caucus presentation given by Elizabeth Eckstrom, MD, MPH of the Division of General Internal Medicine and Geriatrics at Oregon Health Services University in Portland entitled “How Physical Activity Promotes a Healthier Brain”.

A meeting was held with Pat Carroll, legislative director, in the office of Rep. Kevin Yoder (R-KS), whose congressional district includes the IETF headquarters. They discussed essential tremor, its debilitating effects on the quality of life of those afflicted, and

the work of the foundation to raise awareness of ET, work with patient support groups and fund research. Tom and Catherine also asked Carroll to urge Rep. Yoder to join the Caucus.

In addition, the IETF team met with Joe Badger, in the office of Sen. Jerry Moran (R-KS), Julia Latash, with Sen. Clare McCaskill (D-MO), who is a member of the Senate Special Committee on Aging, and Colin Brainard, the health staffer with Rep. Lynn Jenkins (R-KS), a member of the House Ways & Means Committee. Brainard said he would encourage the other two House members from Kansas, whom Tom and Catherine did not have an opportunity to meet, to join the caucus of which Jenkins is already a member.

Finally, the two met with Kristen Donheffner, the legislative director in the office of Rep. Earl Blumenauer (D-OR), who is the co-chair of the Caucus. In addition to explaining the effects of ET to her, they also described their other Hill meetings and their efforts to attract others to join the Caucus. The other co-chair of the Caucus, Rep. Cathy McMorris-Rodgers (R-WA), was unable to meet with Tom and Catherine; however, they were able to leave ET and IETF information behind for her. Both Jenkins and McMorris-Rodgers hold leadership positions in the House Republican Party, so it is important to raise the visibility of ET with both.

Catherine also represented the IETF at the Medicare Brain Imaging Task Force Meeting in Philadelphia. The Task Force consists of 10 members

representing ET, PD, and various physician representatives from academic centers across the nation. The discussion revolved around policies that affect patient access to imaging services in hospital outpatient departments; most notably, DaTscan. While DaTscan doesn't diagnose ET, it can help differentiate ET from tremor due to parkinsonian syndromes (PS). It is important to keep this diagnostic tool available to physicians without interruption of services due to a reduction in fees. There is only one tool in the toolbox, so to speak, for ET patients and to lose that one tool might have a negative effect in the diagnostic process. The IETF will continue to work with GE and Applied Policy to retain reimbursement fees at an acceptable level.

While in Philadelphia, Catherine also met with the editor of *Neurology Now* magazine and an agreement was reached to write another story about ET for National ET Awareness Month in March 2015. As many of you know, *Neurology Now* is a publication of the American Academy of Neurology (AAN). The IETF is very pleased that the AAN sees the importance of raising the visibility of ET again in their highly regarded publication. We thank the AAN and *Neurology Now* for working with the IETF to bring greater awareness to ET. ☺

Meds for Less

According to a Consumer Reports telephone poll conducted nationally in 2013, being able to afford medications and medical bills was listed as the number one financial concern among American adults. In addition, respondents reported that they spend an average of \$59 a month, out-of-pocket, on prescription medications. Twelve percent said they spend even more, a whopping \$100 or more each month, after insurance, equaling thousands of dollars each year.

In order to help cut the cost of your prescription drugs, here are some suggestions:

1. **Ask your doctor for a generic.** The difference between a generic and a brand name medication is the size, shape, color, preservatives and other inactive ingredients in the pills. The active ingredients are identical. The Food and Drug Administration (FDA) regulate generics the same way it does brand names. They are required by law to meet the same strict standards. The real difference is in the price. You can save sometimes up to 95 percent off the brand name price just by asking for a generic.
2. **Discount Programs.** Many retailers offer discount generic drug programs to entice people to their stores. Many of these programs are very low cost or even free to join. Not only could you save with additional discounts on your generic drugs, but many retailers will offer additional store discounts or promotions as part of their program. Common chain stores like Costco, Kroger, Rite Aid and Target all offer programs without any enrollment fee, with drug prices as low as \$4. Check with your local retailer for program details and to see if your medications are covered.
3. **Mail-Order.** Some insurance companies offer discounts if you choose to get your prescriptions filled through their mail-order service. Check with your insurance company to see if they have this type of service available. It could save you time, as you won't have to run to the drug store to get your prescription filled, and some money.
4. **Shop around.** Although it is usually best to get all your prescriptions at a single pharmacy, in order



“The difference between a generic and a brand name medication is the size, shape, color, preservatives and other inactive ingredients in the pills.”

to minimize the risk of drug interactions or other safety issues, sometimes it pays to shop around. If you have a prescription that is not available in generic form or isn't included in your usual store's discount program, call around to other local retailers and pharmacies. If you find one that offers a better price, you can fill your prescription there, or consider asking your regular pharmacy to match the quoted price. ©

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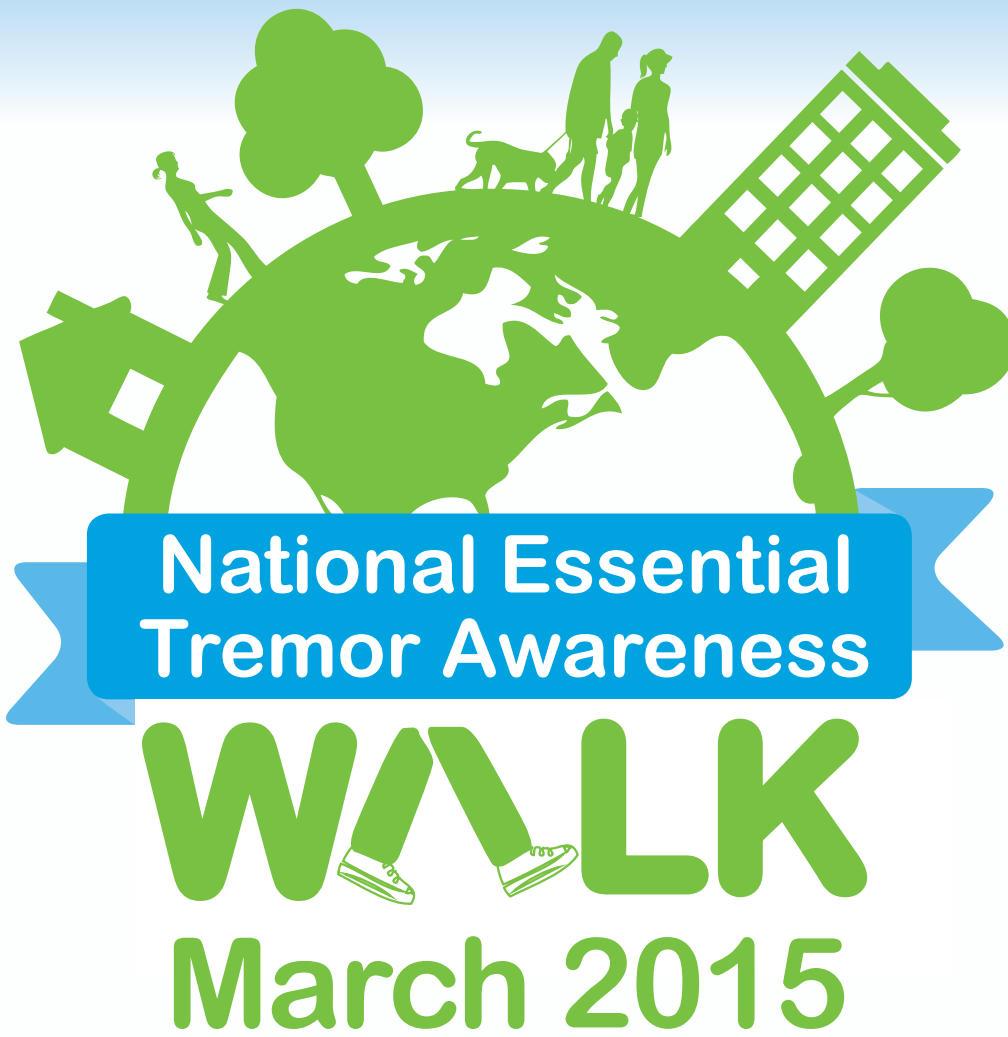
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