

Patients

Family

Caregivers

Professionals

The Quarterly Journal of the International Pemphigus & Pemphigoid Foundation | Fall 2010 • Issue #62

Paving the Path of P/P Research for the next 5 years

In November 2010 the IPPF, along with the **National Institutes of Health** (NIH) will be hosting the third international science meeting. Co-sponsored by the International Pemphigus and Pemphigoid Foundation (IPPF), **National Institute of Arthritis and Musculoskeletal and Skin Disease** (NIAMS), NIH, **Crescent, Centric, Biofusion**, and **Talecris**, among others, the meeting will bring together physicians and scientists interested in these diseases to meet face-to-face and facilitate interactions.

The goal is to identify areas of research opportunity that will promote our understanding of the causes of disease outbreak and flare, and provide experimental and clinical justification for novel treatments of pemphigus and pemphigoid. This meeting is expected to have a dramatic impact on the development of coordinated efforts of the in-

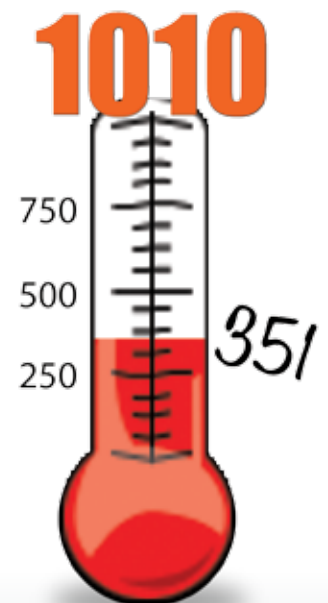
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P-P REGISTRY TRACKER
www.pemphigus.org/registry





As I was planning my letter for this issue, I was wondering about how to communicate the significance of the upcoming November 2010, **P/P Science Meeting**, sponsored by the NIH. As always, creating present-day enthusiasm for a path where manifest change may not occur for years in the future is predictably hard. The P/P Science Meeting is such an event.

Here, doctors and scientists from around the world will gather to share, learn about, and discuss the promising new theories in P/P science that may lead to the next effective (*and less harmful*) P/P treatment. But, it is a long road from here to there. And yet, we must take those small steps to reach the final goal, hard as it is to contemplate the turns in the path.

We recently received news that longtime supporter of P/P patients and the IPPF, **Dr. Jean-Claude Bystry**n passed away from cancer.

Dr. Bystryn has always been able to connect the daily needs of the individual patient with the long-range goal of making an impact on the disease. The "bench to bedside" title of the P/P Science Meeting comes directly from that goal. The Science Meeting has a specific goal to identify key topics at the 'bench' (the lab) and bring those to fruition at the 'bedside' (the patient's daily life). Consequently, the Steering Committee of the conference has voted to rename the third Science Meeting in honor of Dr. Bystryn, making concrete his dream to follow the path, no matter how long and winding it might be, to finding solutions that lead to progress in P/P treatment.

Dr. Bystryn is no stranger to long odds. Born to Jewish parents in Paris in 1938, he and his sister were sheltered by nuns during the Nazi occupation. Reuniting with his parents after the war, the family moved to New York City in 1949. He won a full scholarship to the University of Chicago to study biochemistry and then earned his medical degree from New York University. Dr. Bystryn was a good friend to Janet Segall, founder of the IPPF, and has been a supporter and advisor on the Medical Advisory Board (MAB) of the IPPF since its beginning in 1994.

This quote from Dr. Bystryn sums up his interest in making a difference: *"There's a pleasure and immediacy of taking care of people that you just don't get doing basic research. It makes you appreciate the urgency, the need, and the difficulties of doing work in man. People who just do research sometimes get lost in the mice and the test tubes, and they lose the reality check that you need when you work with people. With medicine, the goal is to help them."*

Many people have called with questions about how to honor Dr. Bystryn's dedicated service to the IPPF. Donations in Memory/Honor of Dr. Bystryn may be made at www.bit.ly/memory-bystryn or by mail and will go to support the **J.C. Bystryn Pemphigus Pemphigoid Science Meeting**. The IPPF will send all acknowledgements on behalf of donors to Dr. Bystryn's family. If you would like to send a personal card to the family, send it in an envelope to my attention and we will gather them all and forward them to the family.

Molly

DAVID A. SIROIS, DMD, PhD President, BOD
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POSTMASTER: Please send address changes to IPPF, 2701 Cottage Way #16, Sacramento CA 95825, United States of America.

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www.pemphigus.org/registry

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You can donate at any time by visiting www.pemphigus.org/donate.

SEPTEMBER

18 What Every American Needs to Know about Autoimmune Disease
Sponsored by AARDA (Cleveland, OH)

27-29 Centric Health Resources' Ultra Orphan Conference
(St Louis, MO)

OCTOBER

2 AARDA's FREE Public Forum "What is Autoimmunity", "Autoimmune Disease in Women", and "Patient to Patient Coping" Open to autoimmune patients, families, and the public. Contact Pat Barber at PBarber@aarda.org
(Cleveland, OH)

26 American Skin Association 12th Annual Gala
(New York, NY)

NOVEMBER

5-6 JC Bystryn Pemphigus & Pemphigoid Meeting: From Bench to Bedside (medical professionals only)
(Bethesda, MD)

APRIL-MAY 2011

29-1 IPPF 2011 Annual Meeting
(Detroit, MI)

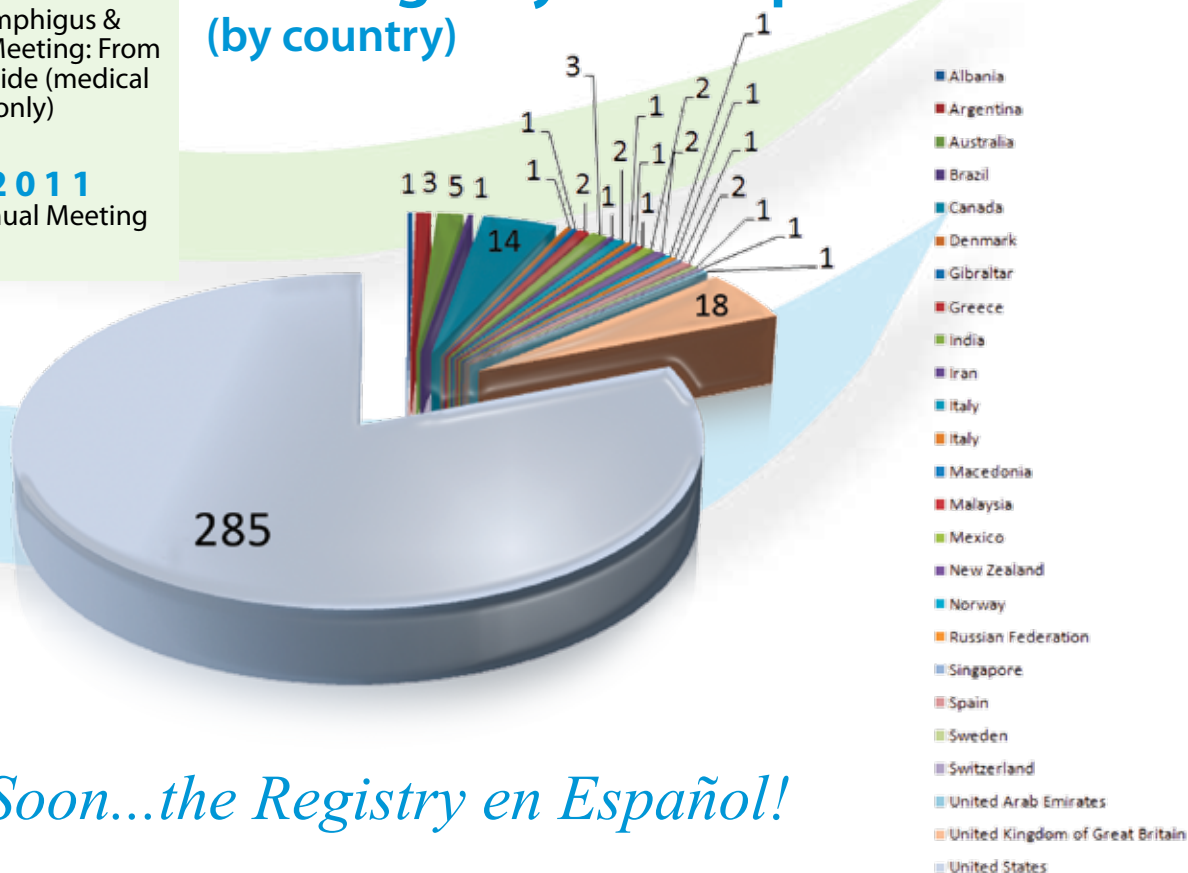
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P-P Registry Participation (by country)



Coming Soon...the Registry en Español!



Advocacy and Education: How one Person Took Her Story to the Professionals

Frequently in conversations with people suffering from one of the various "pemphigal" diseases, one is taken back by how common it is to hear that it took months to be diagnosed -- and even then, most doctors and dentists only had a text-book acquaintance with the vagaries of this disease and the variety of possible treatments. It was clear to me that because this disease does not present often, most doctors are wary of treating it and therefore it is often misdiagnosed. Those doctors not familiar with pemphigus and pemphigoid seem to worry about the sometimes pernicious effects of the drugs that are required and are neither clear about how to manage them, nor do they understand the ways in which the trajectory of this disease manifests itself.

I think this is especially true of the dental community. And of course, what is frustrating about this, is that dentists are the most likely to be the first to see a patient who has these conditions. What often follows is misdiagnosis and unnecessary and sometimes harmful treatments. Even when they have practiced due diligence and correctly diagnosed the condition, they are often reluctant to prescribe Prednisone or to refer their patient to a dermatologist or another doctor.

With that as background, it seemed important to begin to find ways to mitigate this mystery. Since medical and dental practices are now often done in offices or centers with multiple medical personnel, it was a clear and obvious target. One that should be exploited.

I was invited to speak with the dental group at **Blackstone Valley Community Health Care** in Pawtucket, Rhode Island, which is a large facility catering to patients who are either without health care or are charged on a sliding scale. There is a full complement of dentists, oral surgeons, and dental hygienists there and it was a perfect setting to begin this kind of information dissemination.

I was able to use a PowerPoint® presentation, prepared by Dr. **Dave Sirois** and I also put together a packet of information that I could hand out. It contained an IPPF Quarterly (newsletter), the IPPF Informational Brochure, protocols for treatment (based on a survey of specialists in the field), and a list of drugs used in association with pemphigus and pemphigoid.

This was a lunchtime (or brownbag) discussion that was



*Yvette Nachmias-Baeu
Certified Peer Health Coach*

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ternational group that drive the field of immunobullous dermatoses.

Previous IPPF conferences on pemphigus were held on the NIH campus in 2001 ("Pemphigus as a Model of Organ-specific Autoimmune Disease") and in 2005 ("Pemphigus 2005: Progress and Future Directions"). These conferences were very successful and attracted approximately 150 participants each.

The third conference will represent a strong collaborative effort between scientists, clinical researchers, and the IPPF. Drawing from the data provided by committed P/P patients into the IPPF's newly launched Disease Registry, information from more than 350 patients. **We were shooting for 1,000 entries in 2010**, but not everyone has participated so far -- you still can at www.pemphigus.org/registry. By gathering information from as many people as we possibly can -- 1,000 minimum -- we will be able to project a better picture of what this group of diseases looks like, how the diseases are treated, what correlates with remission, drug successes, and quality of life/burden of disease. Armed with this information, we can lobby harder to draw attention to ourselves with the goal of one day being able to promote a better outcome for our community in its entirety.

Even with our goal of 1,000 in mind, 350 records is far more data than we have ever systematically collected before. This information will guide the thoughts of the gathered doctors, on such issues as the effectiveness of early high doses of prednisone, or the results of IVIG or IVIg in combo with Rituximab. In addition, there is hope that there may be data to help predict the onset of a flare before it even manifests!

The support of donations from the IPPF and its partners will facilitate continued work to advance the science and translational aspects of the

studies on autoimmune blistering diseases. The critical involvement of the IPPF assures community and patient awareness about this important meeting. Given the many advances in both the scientific understanding and therapeutic immunologic approaches, this is a timely opportunity.

This conference will:

- Highlight recent **advances in defining the pathogenesis of pemphigus and pemphigoid**, so as to identify areas of research opportunity that will most effectively promote our understanding of the causes of these severe diseases and improve treatment outcomes;
- Discuss the **feasibility of setting up cooperative multinational endeavors**, so as to: i) define agreed upon algorithm to treat patients with pemphigus or pemphigoid; and ii) conduct multi-institutional randomized trials;
- **Respond to patients' requests and needs for better information** and for more rapid progress in the treatment of these orphan diseases, in order to focus attention of the participants on the ultimate need that must be met.

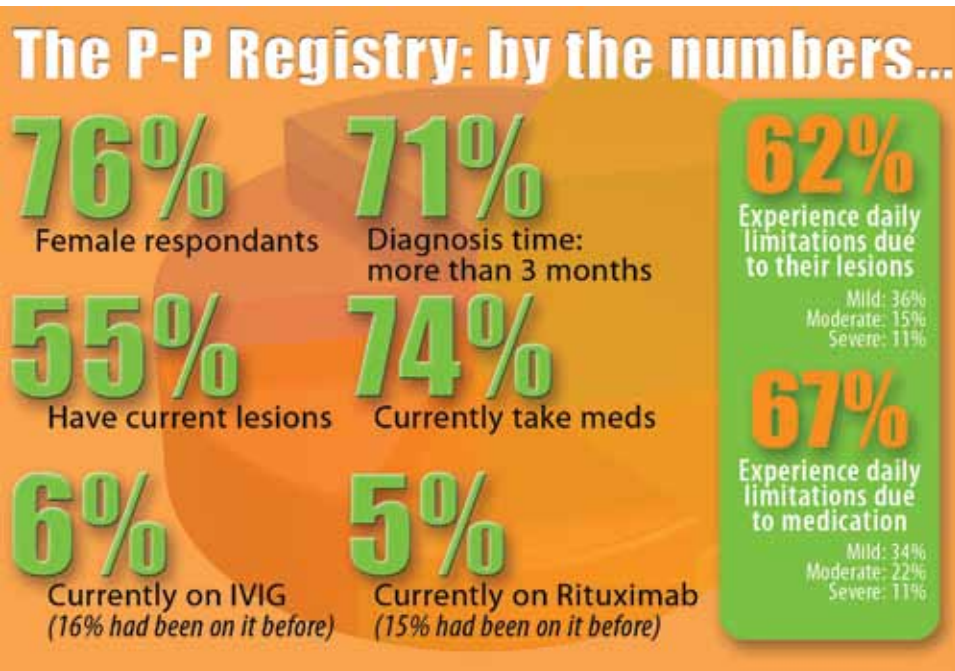
The theme of this meeting touches on a unique facet of public health interest, connecting the basic sci-

ence efforts (the "bench") to their clinical applications (the "bedside"). Both the basic researchers and the clinicians with interest in immunobullous diseases will jointly discuss recently published and as yet unpublished research data and treatment outcomes. The opportunity created within such a focused interest group in an informal environment will contribute to the emerging of novel ideas to resolve existing problems with treatment, and establishing fruitful collaborations.

We hope to generate consensus on the terminology and criteria that should be used to describe in a uniform manner severity of the diseases and their response to therapy.

If you would like more information on the registry, participating yourself, getting your doctor involved, or passing the link to others through Facebook or any ideas you have that may help? Please visit <http://www.pemphigus.org/registry>. You can also contact the Registry Admin at 916-922-1298, ext. 1003.

It is ONLY YOU who can provide the data to eventually realize early detection, better treatments, and ultimately a real cure.





SUPPORT COMES FROM ALL AROUND YOU

Mindfulness... Seasons of Life & Chronic Illness

A painting by Flemish painter Dr. **Hugo Heyrman** has forever changed how I now think of the stages of life. The name of the painting which has touched me so deeply is "City Leaf". There is a special beauty in a single green leaf, that looks perfect, but is actually very vulnerable as it blows in the wind. The leaf is, of course, already dying, but its special beauty in the moment is unmistakable.

We all know, on some level, that from the moment we are born we are dying. This fact takes on a more special meaning when we are diagnosed with a serious chronic illness. There is nothing pretty about these diseases when only observed medically, but we have choices: We can either consider every day as another 24 hours moving us toward death, or we can feel even more alive and appreciate every day even more. Yes, some days are definitely more challenging than others, but we have the choice of being even more grateful to be here and with constantly improving treatments adding to quality of life, or we can be resentful of things we may have to change and activities we may no longer be able to do.


As we (who live in geographical areas which have seasons) go through the summer months, with autumn approaching, we will soon see the beauty of autumn and the changing colors of the leaves. I have vivid memories of

the second skydive I ever did. Just two weeks before the trees were all green and bushy; now it was late September, and I will never forget the sight below me when my parachute opened. It was truly awesome, with all the trees below changing colors and those colors being so beautiful that they literally took my breath away. It was a truly awesome and unforgettable site.

I mentioned this observation to a patient, about how beautiful the fall foliage was, and all he could think of was that they were dying. He was unable to see the beauty in the moment. Hugo's "City Leaf" is still green and beautiful in the moment, but nonetheless dying, as all living things are.

Many physically healthy people reach mid-age (when ever that may be for any given individual) and only see their lives as half over – usually thought to be the best half. For those of us with chronic illness, many of us are just so

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Dr. Terry Wolinsky-McDonald is a licensed clinical psychologist in the Pittsburgh, Pa. area. She is a member of the IPPF Board of Directors and frequent contributor to the Quarterly. Her articles focus on the psychological aspects of living with P/P in patients, caregivers, and family members.

On behalf of the Board of Directors, Medical Advisory Board, Staff and Members of the IPPF, we want to recognize the tremendous loss of Dr. Jean-Claude Bystryn. Everyone in the pemphigus/pemphigoid community benefited from his extraordinary research contributions and unwavering commitment to the patients he both directly cared for and those he indirectly aided through the IPPF.

The medical professionals in this community recall how instrumental Dr. Bystryn was in inspiring more evidence-based research to help those suffering from blistering diseases, and patients are ever grateful for his innovative approaches to translational advances in treating patients.

Reaching ever larger, Dr. Bystryn was one of the key physicians that reached out to others in Europe, India and other countries to collaborate and bring new methods of treatment to the United States. As a founding member of the IPPF Medical Advisory Board and during the past years as its Chairman, his inimitable passion and vision advanced the Foundation and our understanding of blistering illnesses and their treatment.

We are deeply saddened by Dr. Bystryn's passing. We celebrate and are forever grateful for his intellect, compassion, and selflessness. We extend our deepest sympathy to his family, Marcia, Annie and Alex.

*Eternally grateful
for the spirit and
intellect of
Jean Claude Bystryn
1938-2010*



...continued from ONE WAY, page 4

casual and allowed for an open "give and take." There were about 10 professionals present. I structured my talk to be no more than 20 minutes leaving the rest of the time open for discussion and questions. The whole presentation lasted about one hour. The points I covered were:

1. What the IPPF is and does, and what my role in the organization.
2. The "big picture view" of the various types of pemphigoid disorders (how and where they present, what they look like, how they feel, and what treatments/drugs are generally used).
3. Statistical demographics of the disease.

One thing that I felt I needed to emphasize was the importance of performing a biopsy when there is doubt about diagnosis. I talked about doing a proper biopsy and following that up with an equally important tool: the ELISA blood test.

I lightly touched on the **treatment protocols** now available and the real need to follow that patient, or have them followed, medically due to side effects.

It was after all of this that I gave a **personal synopsis** of my own history, and interestingly enough this is what they were most anxious to hear. It was as if I was a concrete representation of what the discussion was all about, and it helped to emphasize the important role dentists and hygienists can and must play in early detection and proper treatment and referral. The positive outcome of being in remission also set, I think, the proper notion, that remission was achievable.

The question-and-answer period was lively and I felt an impression had been made. Now their curiosity and interest had been jumpstarted, I felt positive that this education and awareness process should be done all the time.

My next step is to find other medical institutes I can present to and **I encourage each and every one of you to consider giving your own "awareness seminar" at a local clinic, school, or hospital.** It really is easy to do - and the benefits are worth it!

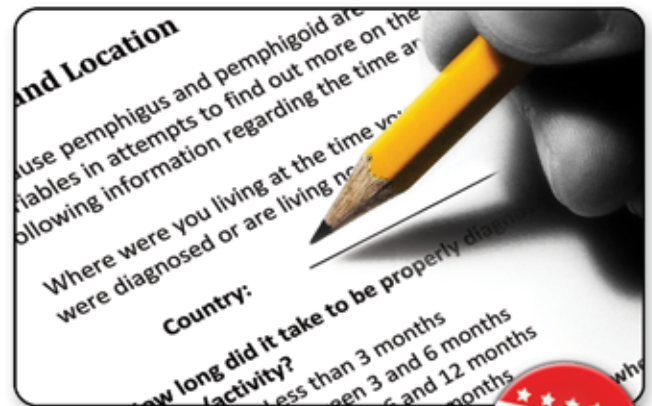
Each health center is typically run by at least one or more medical administrators. They can be contacted and urged to set up these casual seminars. I would emphasize to them that not only the staff physicians, but the nurses, practitioners, and lab technicians all can -- and should -- participate. A free lunch is probably a good inducement as these professionals are busy most of the day and a break with lunch is a good way to draw them in. Talk to the IPPF offices about ways these organizations can support your project.

I was encouraged by my reception and the feedback I got; I had been given "rave reviews." That meant a lot to me -- they had listened -- and more importantly, now this once-abstract disease had become just that much more real.

Oh, and in case you were wondering, *lunch was very tasty!*

Unable to do the Registry online?

We have paper copies of the Registry!



Call the IPPF at
(916) 922-1298 x1002
to have your copied mailed to you

¿HABLA ESPAÑOL?

Nosotros le necesitamos para hablar ambos español e inglés.

¿Querría ayudar otros?

There are many Spanish-speaking people who contact the IPPF for assistance and could benefit from your P/P knowledge and experience.

If you are interested in helping others through our Peer Support Program, contact us at (916) 922-1298 x 1002 or email info@pemphigus.org.

¡Gracias!



in memory

Jean-Claude Bystryn

1938-2010



Husband
Father
Physician
Visionary
Friend

“Doctor Bystryn was more than just a leader in pemphigus and pemphigoid research, he was a dedicated physician who bettered the lives of patients around the world. And he was a good friend. He will be greatly missed.”



I am very saddened to hear the news about Jean Claude. We all benefited from his contributions and commitment to Pemphigus research and clinical care over the years. He will be deeply missed.

*Dr. Animesh Sinha
Michigan*

His passion for the IPPF and leadership helped to move the IPPF forward and become an excellent organization. He was a role model to me and I will miss him. My thoughts and prayers are with his family.

*Dr. Amit Pandya
Texas*

With the passing away of Jean-Claude we lose one of the most important clinical investigators of pemphigus in the last 30 years.

*Dr. Marcel Jonkman
The Netherlands*

Dr. Bystryn was a great friend, strong supporter and a genuine human being. He touched the lives of many people in many ways and made it better for all of them. I will miss him.

*Dr. Razzaque Ahmed
Massachusetts*

He treated me for Pemphigus from 1992 until about 2004 (remission). It was a long relationship, but he brought me to remission. He is leaving a very large void for many.

*Sandra & Herb Fledstein
New York*

The members of the Blistering Diseases Support Group from the Boston, MA area would like to express our heartfelt sympathy at the loss of Dr. Jean-Claude Bystryn. Our feeling of sadness go to his family, to all his previous and present patients and to the entire global community of patients with blistering diseases. We join you in mourning the loss of a great and caring physician and a pioneer and leader in the field of blistering diseases.

*Debbie and Robert Stillman
Administrators, Blistering Disease Support Group
Boston, MA*

I had made plans to go to New York after the IPPF Annual Meeting in April 2010. I contacted Dr. Bystryn to see how he felt about a short visit. In his way, with a just a few words, he said he would be happy to see me. Needless to say, I was quite pleased. Then, when the IPPF decided to give Dr. Bystryn the Founder's Award, I offered to take it to him.

When Dr. Bystryn opened the door, he was extremely thin but his spirits were good. I gave him the award and told him that there were a lot of people out there who cared and were pulling for him. He was genuinely moved. We sat and talked for a while, and even had a little tete a tete about the Healthcare Bill.

He was about to have his final round of chemo and was looking forward to going back to work part-time after recovering from treatment. I left looking forward to his seeing him again.

Some people complained about his bedside manner, and it was something Dr. Bystryn and I had talked about. He told me he really wanted to do better, and that he really cared a lot about his patients. I had no doubt about that.

I am glad he found his way to NY after World War II and grateful to all those who had a hand in saving his life. I am a better person for knowing him.

*Janet Segall
Founder of IPPF*

Although I did not meet the good doctor, I appreciate what he has done for so many patients. It was great to read about his early years and about his zest for life. His spirit remains and will inspire many.

*Mei Ling Moore (PV)
California*

Jean Claude was a very good friend. We used to have a drink of French or Californian wine at each meeting; this will be now only a memory...

*Prof. Pascal Joly
France*

I had an opportunity to thank [his children] and Mrs. Bystryn for the care I received as his patient. They are a gracious family indeed and I am happy that I was able to attend the service.

*Toby Zucker (PV)
New York*

There are so few medical professionals aware of this disease and as dedicated as Dr. Jean-Claude Bystryn. He will be missed by people like me who never met him, but are truly grateful to him

*Frances Garvin (PV)
Maryland*

He was truly a great doctor. He is the reason I'm in remission and have been for quite some time now.

*Debbie O'Connor (PV)
New York*

Dr. Bystryn's professional work and contributions will live on forever for those he has already helped and for those not yet diagnosed.

*Dr. Terry McDonald
Pittsburgh, PA*

a cup of java

with Miki



That southern drawl, charm, and warmth drew me to her like a magnet. I met Lou at the **2010 Annual Meeting** in Philadelphia, where she and her husband **Billy** (who cracks me up) gave me a big old hug. When I looked at her, I noticed she had this gorgeous decorative patch over her right eye. I opened my mouth, inserted my foot and said, "What happened to your eye?"



Name: MaryLou Neeley

A.K.A.: "Lou"

Home: Vicksburg, MS

The day of the birth of her daughter in 1973, she noticed that the vision in her right eye was making objects appear curvy instead of straight. Subsequently, a small tumor was found in the right eye. It was monitored frequently, and by 1978, had begun growing. A biopsy, revealed the tumor to be Spindle B Melanoma, a rare and deadly form of cancer that aggressively spreads throughout her body if left unattended. The specialist recommended complete removal of the eye immediately, and Lou agreed. After removal of the eye, she began wearing a prosthesis. She currently

has two benign tumors in her left eye that also cause blurry and curvy vision, but is now 32 years post cancer.

After losing the eye, there was an adjustment period in everyday life. She had no depth perception and half of her peripheral vision is gone. When walking, it was common for her run into posts, signs, and sometimes even other people. A pinball machine comes to mind -- without bells and whistles. She had to learn once again how to drive safely. Not trusting what she saw in the side mirrors, she would turn her head and look instead. She has adjusted, but still occasionally walks into things. **Note to ask Lou:** *Did you have a bumper sticker that said, "If you don't like the way I drive, get off the sidewalk?"*

In 2005, MaryLou was diagnosed with MMP/CP by way of a biopsy of her inflamed gums. When she learned that it could spread to the eyes and result in blindness, Lou was staring her worst fear in the face; losing the sight in her one remaining eye. Eye specialists she had been seeing did not know enough about the disease to offer any guidance.

Searching the Internet, Billy found **Dr. Irving Raber** at the **Wills Eye Institute** in Philadelphia. Upon examination, Dr. Raber saw no evidence of MMP/CP in the left eye. However, the MMP/CP had attacked the socket of her right eye, where the blistering and scarring had already forced her to discontinue wearing her prosthesis in favor of a patch. Tiring of people staring at a plain patch, she had the gumption to give them something to stare at!

Lou first began using rubber stamps on the patches, then coloring in the figure. Because of the time and effort required to color the patches and make them look good, she began using temporary tattoos instead of the stamps and coloring. This was much faster and easier, and garnered positive reaction. Smiling people often approach her for a closer look, thinking that she has tattooed her eye, and then compliment her on how good the patches look. They even laugh when an application with something funny, such as a big, moving googly-eye stares back at them.

Continued on page 14...

questions & answers

Questions from forums, email, phone calls and Facebook postings Answers from the IPPF Peer Health Coaches

Q: I've heard of some success with tacrolimus ointment for BP -- thoughts?

A: Some doctors report success with tacrolimus ointment for BP, that it can help limit the use of more potent topicals such as clobetasol, especially in atrophy-prone areas of skin (vulva/anal). However, also note its black box warning and side effect of malignancy risk. Albeit a controversial and by no means universally accepted risk, the FDA labeling remains. Discuss uses and side effects of this as compared to other options fully with your doctor.

You can download an information sheet at <http://bit.ly/????>.

Q: Which of the insurance companies cover newer biologic therapies and what can I do if mine insurance is resisting?

A: From what we know currently, although insurance formularies (*list of covered drugs*) change frequently, for IVIg; **United Healthcare** considers it experimental. If you are up for the fight, they will approve it on appeal. If prescribed, a Letter of Medical Necessity can be submitted for a special request, often granted. **Blue Shield of CA** considers it experimental as well. Some **Medicare Part D** plans will not

cover at home. But Medicare will certainly cover it in the hospital. You can always call the IPPF and we can get you a referral to an insurance advocate if you are having trouble.

For Rituximab, most insurance companies will want justification, but most will cover in the end. Often what it takes is evidence in the form of scientific support -- articles on research and treatment -- soon data from the **IPPF P-P Registry** will likely provide evidence regarding its treatment benefit.

Q: I'm searching for a new calcium supplement and would appreciate your feedback. Due to having osteopenia, I am anxious to find a supplement that will be beneficial. Researching it online proved to be overwhelming. It seems like anyone and everyone are trying to sell the "best" supplement known to mankind. I want one that isn't overly expensive, absorbable and possibly proven to promote bone strength and regrowth. All my docs recommended Fosamax, Actonel, Boniva and Citracal. I'd prefer not to go the Fosamax route.

A1: I had been told to take Calcium by my doctor because I have some Osteoporosis, and I found the best has been by **Vitamin World**. They make

their own vitamins. I get 500 mg, absorbable Calcium with Vit. D. 1000mg, and have to take each one with my three meals a day. At the IPPF Annual Meeting we were told that our bodies can only absorb 500mgs. at a time, which is why it is taken with the three meals, and my doctors say I am in great health. I also take omega-3 at two of those meals, since it's important, too.

A2: I like the **Country Life** brand of liquid calcium/magnesium/vitamin D. It is more easily absorbed since it is in a liquid form. I was also able to purchase the mineral Strontium by Boiron while I was in France. We (*IPPF members in the Forums and Discussion Group*) had a discussion about this mineral and its improvement of bone density several months ago. The strontium should not be taken within 2 hours of taking calcium. There are many places that sell Boiron supplements, but I have not seen that their Strontium products are available in the US, but maybe online? I, too, would avoid the bisphosphonates (Fosamax, etc.) due to rare but potential side effects such as atrial fibrillation (which my mom developed while on Actonel), and the potential jaw bone problems. Since you do not

yet have osteoporosis, I'd give the non-prescriptive route a try.

Keep in mind that every patient reacts to medications and other solutions differently. Most of this advice is from PERSONAL experience and may not be appropriate for you. Discuss all changes you make to your treatment plan with your doctor.

Q: What is the Health Management Program (HMP)?:

A: The IPPF's **Health Management Program** is a voluntary program with no downside or cost. All the data collected is confidential. HMPs help patients achieve better health and quality of life by increasing knowledge and awareness about pemphigus and pemphigoid issues, practices, and new developments. **HMP Coaches** (*Marc, Yvette, Susan and Sharon*) will remind you to discuss certain issues with the doctor such as bone density, lab tests, and eye exams.

Most useful for those new to the complexity of these diseases, the program puts an experienced P/P patient in your "back pocket", giving advice, perspective and questions to ask your doctor. Enrollment is simple. You will be contacted by a **Peer Health Coach** who can answer your questions and provide you with the Enrollment and Consent Form. After we receive your consent form, your Peer Health Coach will call or e-mail you to set up an appointment to complete our initial survey which should take approximately 30 minutes.

For more information visit <http://www.pemphigus.org/hmp>.

For those who are in good control and have a good understanding of P/P, you can give back to the IPPF and to those newly-diagnosed by participating in the Disease Registry. Also confidential, the data collected there illuminates areas of success (and lack) in treatment strategies and in fruitful areas of lab research. We need 1,000 patients to make statistically significant plans and there are just over 350 histories enrolled. Do make a difference for others even if you are feeling better at www.pemphigus.org/registry. This data will give researchers a better chance to find treatments with less negative impacts for generations to come, and ultimately help find a cure.

Can **YOU** Answer the **Question of the Month?**

Q: I have pemphigoid and am on 15mg/day of prednisone for about one year. I am 7 months pregnant and starting to get "pins and needles" sensation running through my fingers, mainly the tips. Anyone have any ideas/experience is this from BP and pregnancy or one or the other?

If you have been pregnant with pemphigus or pemphigoid and have experiences to share, please join our Facebook® group at http://bit.ly/ippf_fb, the IPPF Forums at http://bit.ly/ippf_forums, or email Molly at molly@pemphigus.org.



Your participation in the
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today
can help improve care and
develop better medications for
tomorrow.

Wouldn't it be nice if others like
David here didn't have to
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pemphigoid because you took
15 minutes to provide data
and
researchers found a cure?

www.pemphigus.org/registry
15 minutes...it's worth it!

INTERNATIONAL LINKS TO SUPPORT

CANADIAN PEMPHIGUS AND PEMPHIGOID
FOUNDATION (CPPF)

<http://www.pemphigus.ca>

AUSTRALASIAN BLISTERING DISEASE
FOUNDATION (ABDF)

<http://www.blisters.org.au/>

ASSOCIATION PEMPHIGUS - PEMPHIGOÏDE
FRANCE (APPF)

<http://www.pemphigus.asso.fr/>

ASSOCIAZIONE NAZIONALE PEMFIGO/
PEMFIGOIDE ITALY (ANPPI)

<http://www.pemfigo.it>

NETWORK NEDERLAND VOOR PEMPHIGUS
EN PEMFIGOÏD (NNPP)

<http://www.pemphigus.nl/>

PEM FRIENDS (UK)

<http://www.pemfriends.co.uk>

SPANISH FACEBOOK GROUP

<http://tinyurl.com/ippf-facebook-es>

If you have a group you let us know so
we can help spread the word!

...continued from A CUP OF JAVA, page 11

Lou continues making patches, even though at times does not feel like doing it. Nevertheless, in the brief moment of joy seen in the faces of people who see and appreciate the patches, she finds the encouragement to continue making them. She does seasonal patches for holidays and special occasions. Oh, and they must ALL be color coordinated with whatever clothing she is wearing. (*Meanwhile, I am the one walking around with a striped shirt and checkered pants!*)

Not satisfied with answers or treatments by doctors that had examined and treated her; she continued her quest on the Internet. She connected with **Molly Stuart** at the IPPF who put her in touch with **Marc Yale**, a Health Peer coach. Marc also has MMP/CP. He referred her to his eye specialist in Boston, Dr. **Steven Foster**. In addition to her trip to Boston to see Dr. Foster, Lou felt that her trip from Mississippi to Boston would be wasted if she did not also pay a visit to Dr. **Razzaque Ahmed** while there.

It helps when we can focus positive energy upon getting well rather than dwelling on the negative "poor me."

Dr. Ahmed examined her in his office that afternoon and determined the MMP/CP to be active in all other areas of mucosal tissue that he could visually see, and at an advanced state. He described the MMP/CP in detail, including a two-year course of treatment that could put the disease into remission. Despite her initial fears of another letdown, his compassion, knowledge, and confidence made her ecstatic!

Lou is currently about one year into her treatments, starting with Rituximab, and the mucosal activity initially subsided. Despite her monthly IVIG treatments, she is developing painful lesions on her chest, back, scalp, and arms. There is also evidence that the mucosal areas are beginning to flare again. Her hematologist at the University of Mississippi Cancer Institute has already begun administering 12 more weeks of Rituximab in hopes of bringing it back under control.

In spite of this setback, she remains upbeat and determined to win her wrestling contest with the MMP/CP. It pleases her that the staff at the Cancer Institute comes to see her just to gander at what is on her patch each treatment day.

With daily fatigue and constant pain, she is overcome with a pity party a few times a year. However, Billy, her rock/hillbilly psychologist, will intervene after a day or so. Lou says of Billy, "It is not his nature to be overly affectionate, but when I need him most, he listens to me patiently, holds me and tells me that he loves me regardless of my physical condition. He says that I am still the same woman that he loved and married in 1991, and will always feel that way. Therefore, I need to turn



*Miki Pangburn (PV)
Part-Time Writer
Full-Time Coffee Drinker*

off the tears, leave the pity party, and get on with enjoying the many good things in our lives." After his reassurance, she is able to pull herself together, begin feeling good about herself again, and enjoy life.

Lou states, "It helps when we can focus positive energy upon getting well rather than dwelling on the negative 'poor me.' We must first do what we can to help ourselves, follow the guidance given to us by skilled and learned physicians, and finally look for ways to help someone else. Helping others takes your mind off your own problems, and you frequently find someone whose problems are worse than your own. If a person is willing, they can use the experience of their own ordeal to assist others with similar health problems, showing them first hand that there is hope. That is the ultimate reward in life."

Her grandson **Ryan** calls her **Jammaw Patches**. Me? I call her **special!**



Author's Note: Lou loves the idea for children and adults who may have to wear eye patches in their own lives to mass-produce them (i.e. bandage manufacturer), but she only has two speeds – fast and stop. If any readers know people who may be able to help point her in a direction for this to happen, please email me at nutnbolt3@comcast.net.

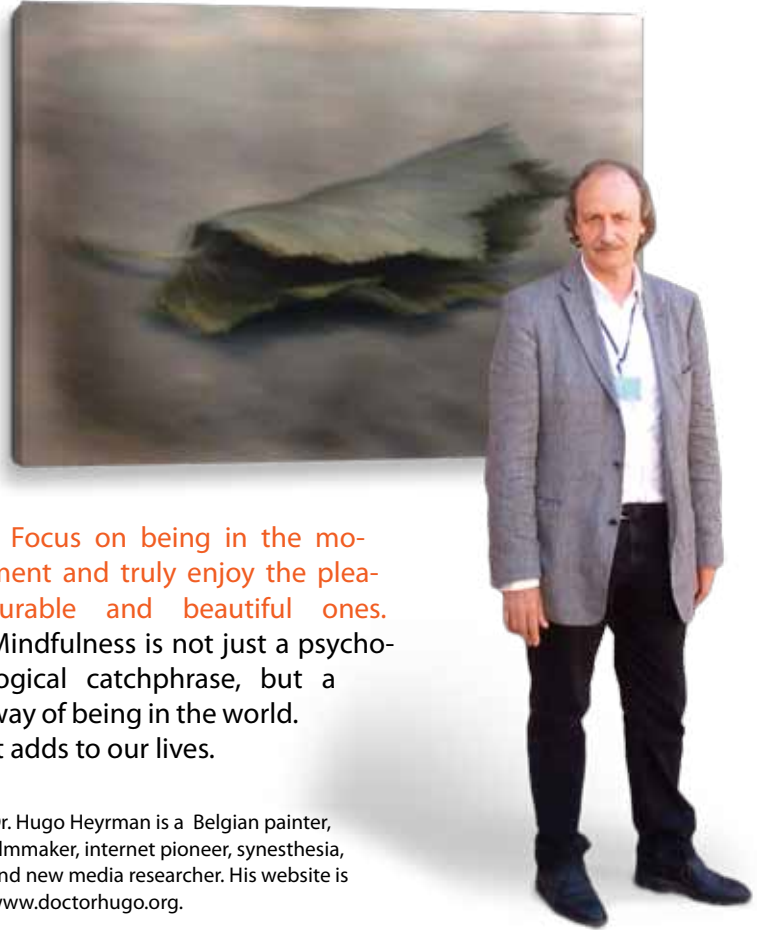
...continued from MINDFULNESS, page 6

grateful to be alive and treatable that we more deeply appreciate every day we are given, once the illness is under reasonable control. We don't think of our glass as half empty, but rather either half full or a glass that still contains water. In a way, these illnesses help put things in perspective, much like that second skydive did for me. There are so many more beauties in life than most people see. I think that was why the Tim McGraw hit song "Live Like You Were Dying" resonated with so many people.

"Mindfulness" can be thought of as the opposite of "mindlessness", just going through the motions of everyday life vs. "being in the moment". For a number of years the psychological term "mindfulness" was just another catch phrase; however, now the research is proving to us that **mindfulness cognitive therapy** is having a great deal of validated success in a wide range of areas. I always keep the lighting in my office low, with lamps versus overhead lighting, and there is always a candle on a table between sofas and chairs. Sometimes, after teaching a patient to slow down and deepen their breathing, I will ask them to just focus on their breathing and the candle. I will then systematically turn off all of the lamps. Patients always report reduced anxiety and stress levels with just this one simple exercise.

As autumn approaches for many of us, and leaves change colors as they begin their fall from the trees, pay close attention to the beauty in the fall foliage. **Try to just stay in the moment**, and you will experience a decrease in stress levels and intrusive thoughts. You will be amazed at how easily this is accomplished. Once diagnosed with your (or a loved one's) illness it may feel like the autumn of your life. Remember that after the leaves all fall and most trees are

bare, the winter will lead into the emergence of spring – a rebirth in a way – with summer not far behind with its own special beauty. Allow yourself to thoroughly enjoy the autumn season, knowing that it is taking us into a new season and that the cycle will continue. Many people say that a picture is worth a thousand words. In the case of "City Leaf" this is very true.



Focus on being in the moment and truly enjoy the pleasurable and beautiful ones. Mindfulness is not just a psychological catchphrase, but a way of being in the world. It adds to our lives.

Dr. Hugo Heyrman is a Belgian painter, filmmaker, internet pioneer, synesthesia, and new media researcher. His website is www.doctorhugo.org.

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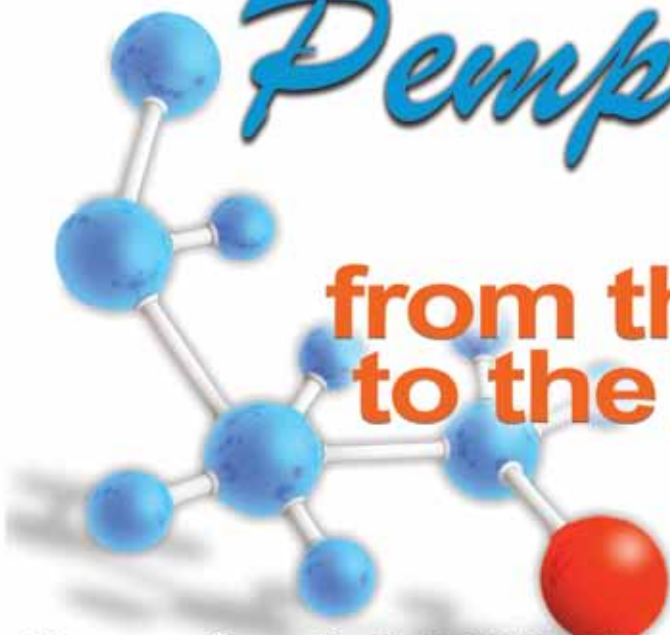
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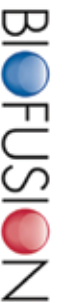
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