Have you ever had a question about pemphigus or pemphigoid, a certain medication, or a treatment protocol and you just can't get a straight answer from your physician? How about wanting to know more than you already do about your disease and how to live with it? Well, the IPPF has a way to help: our FREE Town Hall Conference Call series.

The IPPF has now conducted three of these calls and feedback has been tremendous! The sessions are free, feature a leading P/P physician from the IPPF, and are done in a Q&A format moderated by IPPF Senior Peer Health Coach Marc Yale.

The calls last one hour and callers are able to ask the doctor a primary question and a follow-up question before allowing the next caller a chance. Callers may enter the queue as often as time allows, but should keep in mind the goal is to allow many people to ask questions. Often, hearing other questions will answer some of your own.

Additionally, questions can be sent to townhall@pemphigus.org during and after the session. If you miss a Town Hall or want to re-hear the session, audio files are available in MP3 and .zip format at www.pemphigus.org/townhall about 48 hours after the call has ended.

If you have questions about the Town Hall Conference Calls, want to recommend a speaker or an idea, email townhall@pemphigus.org or call (916) 922-1298 x1003.

(Please note that callers must pay for any charges incurred in dialing from their phone to the Southern California extension)
Greetings!

Usually after the Annual Meeting as the days blend into Summer, we have a period of quiet time at the office to clean off our desks, unpack boxes and follow-up on all the new opportunities generated from the meeting. This year, there were so many new opportunities there was little time to "dig our toes in the sand", although Will did manage to take a break to get married and I vacationed away my "day to get a year older."

Here's what we're juggling:

Already it’s time to prepare for the 2012 Annual Meeting. Save the date for BOSTON May 18-20, 2012, and see more info at www.pemphigus.org/annualmeeting. Terry Wolinsky-McDonald, Sonia Tramel, Greg Wright from the BOD, and Will Zrnchik are working closely with Dr. Razzaque Ahmed and the Blistering Diseases Clinic and other area leaders to host one of the largest and most informative meetings ever. If you have skills that could add to the organization or fundraising for this meeting, please contact me at molly@pemphigus.org.

Your Board of Directors approved a budget for a research study of delays to diagnosis. It’s a short online survey to document where people go when they have symptoms and what doctors are doing and saying -- the ones that go awry and the ones that help. This will allow us to identify key areas where education and outreach can move the lever to better diagnosis and allow us to apply for grants to fund this education. If you were diagnosed within the last 18 months please answer this survey (see page 3) -- there are likely 300 new P/P patients a year in the US and we need over 100 to be secure in valid survey results.

I have been working to develop inroads in the Pharma industry, attending several drug development conferences and having meetings with many pharma companies to generate research opportunities based on the data in our Registry and opportunities for basic science through blood and tissue donations. In addition I have been speaking with Medical Advisory Board members and small bio-tech firms to generate interest in research projects on drug compounds that my be effective with disease mechanisms that cause P/P.

I’ll be off again shortly to an Orphan Drug Industry Conference and then to Washington DC to advocate with the NIH (www.nih.gov) and NIAMS (www.niams.nih.gov) for increased funding in the orphan and autoimmune areas. In the meantime, contact Will at the office or Marc Yale and his team of Peer Health Coaches if we can assist with anything.

Happy Fall,
Recently Diagnosed?

If you, or someone you know was diagnosed since February 2010, then we have a favor to ask!

We are able to reproduce articles and provide electronic copies of issues. The cost for this service varies based on the amount and type of media preferred. If you are interested in submitting a story for print consideration, please contact the IPPF prior to submitting your story. Our staff will assist you in preparing your article for future publishing in an issue that relates to your topic.

BOARD OF DIRECTORS
David A. Sirois, DMD, PhD President
The Honorable Janice A. Taylor Vice President
Lee A. Heins Secretary/Treasurer
Dan Goodwill Director
Paul Konowitz, MD, FACS Director
Rebecca Oling, MLS Director
Badri Renganarajan, MD Director
Sonia Tramel Director
Mindy Unger Director
Terry Wollinsky-McDonald, PhD Director
J. Gregory Wright, MBA Director

MEDICAL ADVISORY BOARD
Victoria Werth, MD University of Pennsylvania, Philadelphia PA
Sergio Granda, MD, PhD, DSc Univ. of California-Irvine, Irvine CA
Grant Anhalt, MD Johns Hopkins Univ. Med Center, Baltimore MD
Luis Diaz, MD University of North Carolina, Chapel Hill NC
Russell P. Hall III, MD Duke Univ. School of Medicine, Durham NC
Takashi Hashimoto, MD Kurume Univ. School of Medicine, Japan
Michael Hertl, MD Philippus-University Marburg, Germany
Pascal Joly, MD Rouen University Hospital, Rouen, France
Marcel Jonkman, MD, PhD Univ. of Groningen, Netherlands
Francesco A. Kerdel, MD Univ. of Miami Medical School, Miami FL
Neil Korman, MD, PhD Case Western Reserve Univ., Cleveland OH
M. Peter Marinkovich, MD Stanford University, Stanford CA
Dede F. Murrell, MD University of New South Wales, Australia
Amit Pandya, MD University of Texas Southwestern, Dallas TX
Animesh A. Sinha, MD, PhD SUNY-Buffalo, Buffalo NY
David Sirois, DMD, PhD New York Univ. College of Dentistry, NY NY
Robert A. Swerlick, MD Emory University, Atlanta GA

ADMINISTRATIVE STAFF AND SUPPORT
Molly Stuart, JD Chief Executive Officer / Senior Editor
William Zrnchik, MBA Director of Communications / Creative Design
Marissa Way Administrative Assistant
Kevin Cruz Cristo-Rey High School, Sac. CA - Intern

PEER HEALTH COACHES
Marc Yale marci@pemphigus.org
Yvette Nachmias-Baer yvette@pemphigus.org
Susan Gonzales-Thomas susan@pemphigus.org
Sharon Hickey sharon@pemphigus.org
Jack Sherman jack@pemphigus.org

HEADQUARTERS
2701 Cottage Way • Suite 16 • Sacramento, CA 95825
Phone: 916-922-1298 • Fax: 916-922-1458
info@pemphigus.org • www.pemphigus.org
© 2011, International Pemphigus & Pemphigoid Foundation. All Rights Reserved.
Printed in the USA by Sundance Press, Tucson AZ
www.sundancepress.com
For a long time I just used the website for information, I didn’t use the forums system and the opportunity for sharing information with other people in the same situation.

After a long period of downtime in my treatment of my PV, I decided to do something about it myself – I didn’t want to sit back and wait for something to happen any longer. I posted 2 or 3 short messages on the forums, and within a week I got contacted by Sharon Hickey who is a Peer Health Coach in the IPPF – and ever since she has taken me under her wings.

My name is Signe and I am a 22-year-old girl diagnosed with PV 5 years ago. I am from Denmark and there is not a lot of information about pemphigus. Because of the missing information and lack of success in my treatment, I turned to the Internet for help. It quickly became clear to me that the information that is online is mostly in English, and one of the websites that popped up on Google was the IPPF website.

The 2011 IPPF Annual Meeting

It is a long way from Denmark to Detroit, and that definitely made me and my family think twice about attending the meeting! :) After some thinking, and the fact that no new attempts to treating my PV were going to happen – we decided to travel the distance and collect information.

My mother and me left Denmark not knowing what to expect from this trip - and not knowing what to get out of the Annual Meeting.

Continued on page 8...
Changes to Human Subject Research Rules
The government is proposing sweeping changes in the rules covering research involving human subjects, an effort officials say would strengthen protections while reducing red tape that can impede studies.

Read more at http://wp.me/p1w91A-Ru

A New Lease on Life for Chris Stein and Blondie
By 1982’s The Hunter, Blondie’s commercial peak had passed, the band was in personal and financial disarray, and a split was inevitable – especially after Chris Stein was diagnosed with pemphigus, a rare autoimmune disease that causes blistering of the skin. With Harry taking several years off to nurse Stein back to health, Blondie appeared to be history, with a perfectly constructed set of pop classics as their legacy. Now Blondie is back and touring once again.

Read more at http://wp.me/p1w91A-QTu

CLINAL TRIAL: Clinical Efficacy of Adjuvant Immunoadsorption in Pemphigus
IPPF MAB member Dr. Michael Hertl announced an ongoing therapeutic study in pemphigus in Germany. This study aims at investigating whether adjuvant immunoadsorption helps to induce faster clinical remissions in patients with acute onset or refractory pemphigus.

Read more at http://wp.me/p1w91A-DJ

Drug Policy Needs Review
Nanaimo dermatologist Dr. Gabriele Weichert won a tiny victory with the provincial PharmaCare program when the agency agreed to cover the off-label use of a costly autoimmune drug for a patient with a rare skin condition. Elizabeth Williamson, 54, has pemphigus, a disease that causes sores on the upper body.

Read more at http://wp.me/p1w91A-Fb

The new IPPF website offers patient and caregiver support and information in one location. Creating a FREE account shares access to additional resources like the Patient Forums. Visit today at:

www.pemphigus.org
Where to start? In this column, I often talk about the importance and empowerment of education. At the last Annual Meeting (in Detroit) Rebecca Strong gave the Keynote Speech on "The Power of One" and told of the empowerment and satisfaction she derived from sharing her own experiences with a rare and difficult to diagnose/treat illness. Not only did she have a surprisingly cathartic experience, but the professionals with whom she shared the information took away more than just facts: they were touched by the reality of what these diseases do to the patient living with them on a daily basis. Because of the emotion attached to the facts, the information is likely to be remembered longer by the audience.

When I presented Continuing Education for the University Dental School in Pittsburgh I did not allow them to label my talk "Pemphigus," but rather "Pemphigus: What You Don’t Know May Kill Someone." It was clearly no regular talk, and the older practicing dentists were enthralled during the presentation, and asked very good questions. Even after the next speaker, an Oral Surgeon, began his presentation, many dentists were lined up with questions for me. Not only did they not know the basics, they recognized the importance of early diagnosis, how to make it, and the consequences when they are not on top of their game. Several were actually concerned they had recently misdiagnosed patients and said they planned to do immediate follow-up. The doctor in charge was especially impressed and made a point of telling me.

Continued on page 9...
PEM Friends founder Carolyn Blain named Patron in recognition for her many years of dedicated support to P/P patients around the world.

The IPPF would like to extend our deepest Congratulations to Carolyn and the honor of being named Patron of PEM Friends. Carolyn's work over the years has been both instrumental and inspiring to others around the world.

Carolyn received the 2011 IPPF Star Award for Patient Support during this year's Annual Meeting in Detroit (she was unable to attend). Congratulations Carolyn and PEM Friends! We wish you many more successful years!
Friday evening was the first time we met with IPPF, the people in the organization and other patients. We were greeted with such warmth and kindness that it blew us a little away. The welcome reception lasted for 3 hours, and what a 3 hours! In that time I got to talk with people who have PV themselves, which is an experience that means much to me. For the first time of the 5 years I have been diagnosed with PV, I felt that someone really understood me. I didn’t have to explain how it hurts in my mouth, I didn’t have to explain all the emotions that come with being diagnosed with such a rare disease – I felt a connection with these people right away.

Friday evening was very overwhelming for me. I got to tell my story to people who really seemed to care, and knew what I was talking about. When the evening was over I had made contact with other patients and doctors.

One of the doctors I met at the annual meeting was Dr. David Sirois from New York. I told him my story, and that I had never been in remission for five years – still on prednisone, and he was so kind to take me in for a consultation the following week, when I came to New York.

The consultation was very giving because Dr. David Sirois really cared and was willing to get in touch with my doctor in Denmark. He also gave me some tips to use in my daily routine of keeping my mouth and gums clean. Finally he made a treatment plan, that I am following now – and so far it is going very well.

After this trip I almost feel like a new person. The whole experience of the annual meeting has been so informative, and I have learned that you don’t have to put your life on hold even though you have a rare disease. It is possible to get better, you just need to get the right information, and that is something the IPPF and an annual meeting can give you. It was my first meeting, and I can only recommend other patients to go – it will change your life.

I would like to thank all those who attended in the meeting in Detroit, for making my trip so positive and giving. A special thanks to Dr. David Sirois for taking your time to see me and to Sharon Hickey my dear Peer Health Coach.

“I couldn’t have done it without you”.

Signe Horn Thomsen
While not everyone can make a presentation as Rebecca and I and others have done, everyONE has the ability to make a contribution of some kind. Some people give of their time and/or expertise. Others make the effort to help in various ways, and many contribute money when they can.

I often tell patients to take on the mindset of professional athletes. Even when not confident they can accomplish something (e.g., the NFL's Pittsburgh Steeler Hines Ward on last season's "Dancing With The Stars"), they do not waste time on negative thoughts; rather, they use positive self-talk as recognized psychologist Donald Meichenbaum, PhD has advocated.

In sports, athletes don’t think "I can’t make that basket, catch/hit that ball, or make it to the finish line." Rather, their mindset and positive self-talk is, "I can do this." Although we may not all be able to be athletes, we can certainly think like them. Try it; you may actually surprise yourself at how positive thinking and self-talk can change your encounters with others and with your own responses to others.

I vividly remember my definitive diagnosis in 2001 and professionals all around me predicting I may not even have six more months to live based on the severity of my symptoms and inability to take systemic prednisone. Back then, only one of the expert dermatologists seemed to believe in the positive effects of IVIg, while others doubted the efficacy of this drug in these diseases, especially if given more than one or two treatments.

This did not deter Dr. A. Razaque Ahmed from going to Washington, DC to advocate for the use of IVIg approved for our rare illnesses. And, he did not stop with getting it approved only for his home state, but rather for all states: The power of one.

To this day, I totally believe Dr. Ahmed saved my life and I couldn’t be more please to be co-hosting with him, the IPPF Annual Meeting in Boston in 2012! (Save the Date!) I still suffer very difficult symptoms from both PV and Sjogren's syndrome, but I am alive after 10+ years and have quality in my life. I am so glad to still be alive, albeit with alternative treatments.

In September of 2002, when I was able to start eating again and no longer losing weight, I made "cold calls" to various local personalities. The medical correspondent for my local ABC affiliate was willing to take my story on. She did her homework and also interviewed both me and my dermatologist at the time. It was a powerful 5 minute piece, and was repeated numerous times over the weekend, reaching a larger audience and saving lives. That’s me—thinking outside the box. When we ask people for or to do things, the worst thing they can say is "no", which is not the end of the world.

I believe it is important to continue to build on the Power of One, and want to take advantage of the momentum. I am asking everyone to think positively and to not be afraid to put yourself "out there". There is not even a race for the cure at this time, but remember that every positive step brings us a step closer.

We have already made amazing progress, and it will not stop here. We do have better treatments, and hopefully a cure will be in the not too distant future. If not for us, then maybe for our descendents or someone else perhaps not yet born or diagnosed. This is why we can not stop our great challenges, many behind us and others ahead.

Your Board of Directors has important and special visions for the IPPF. If each of us can save a life or have a positive impact on others, can you imagine how wonderful that will be? Imagine the impact on so many others if we build on "the power of one", so just imagine the power of hundreds. Let's not allow this opportunity to pass by!
Meet Jack

Peer Health Coaches are more than just helpful ... they're patients, too!

Who am I? I'm Jack Sherman, Peer Health Coach with the IPPF. I have a degree in music education and once played bass professionally. I have packed fish, was an award-winning photographer, and worked as IT technician for several companies in the Seattle area. Currently, besides being a Peer Health Coach I have my own greeting card business, and enjoy helping others do the same. I think the common denominator with my passions are two things: creativity and helping others. That is a commonality that these very different fields have.

I have an awesome 19 year old son, Cameron, and a loving partner, Julia. I was born and raised in the Seattle area. Currently I live about 25 minutes East of Seattle in Issaquah. I love Issaquah; it's close to the city, but also close the the mountains. Issaquah is known nationally for at least one thing: it is the corporate headquarters for Costco. I got your attention now.

I was diagnosed with pemphigus vulgaris in 2002. I wanted to become a PHC because I wanted to help others weave their way through this disease.

I was actually scared to contact the IPPF when I was early in my treatment. Once things were under control, I was ready to give back. I was so charged-up to find that there was a small -- but powerful -- organization dedicated to supporting me and others with this rare disease that I had to get involved! My PHC, Marc Yale, helped me become a PHC...he is an awesome guy, as is the whole team! I'm here to help and would love to answer your P/P questions. You can reach me by email at jack@pemphigus.org.
Advocating for Patients at Drug Information Association Conference

Bridging the gap between what patients' hope & fear in clinical trials

by Molly Stuart, IPPF CEO

Chicago, USA: The IPPF participated in the Drug Information Association's first Patient Fellowship Program, meant to enhance the participation of patient advocacy groups at DIA in order to develop, strengthen and support patient group collaboration with healthcare policy makers, medical professionals, industry representatives and academia.

The IPPF was one of 15 patient organizations selected out of over 50 applicants to receive a grant for all attendance costs. I attended along with CEO's of other patient groups such as the Myasthenia Gravis Foundation and the Pancreatic Cancer Action Network.

The goal for everyone was to try to strategize ways that we can bridge the gap between what patients hope and fear about clinical trials. (Clinical trials are used to explore if medications or treatments are safe and effective. For example, they might have someone keep a food diary and look for signs of a dairy allergy. At the more extreme end, they might follow a pemphigus patient taking methotrexate to see impact there.) We also worked in groups with researchers at universities and industry to discuss how they might improve things for patients who are participating.

We discussed dis-incentives to patients to participate such as scary media stories, uncertainty about how the process works, lawyers and legalese in complicated forms, fear from family members, fear that might not get a “real” medicine, too much time or expense.

And yet, every where I turned I heard patients speaking out about how much they had gained from participating in trials. In the most dramatic cases I heard stories of some who got better medical care than they could have afforded and some who used treatments they otherwise wouldn't have been allowed.

On a more mundane but extra powerful level participants talked about how good it made them feel to know that they were improving science and therefor improving hope for anyone who comes after them.

A true sense of their efforts on behalf of a wider community.

Around here we call that, The Power of One!

Molly

I WANT THE QUARTERLY!
Your source for the latest in P-P research and dedicated patient support.

Copy or cut out this form, print clearly, and return with your donation to:
IPPF • 2701 Cottage Way #16 • Sacramento CA 95825

☐ Enclosed is my tax-deductable donation of $50.00
☐ Enclosed is my tax-deductable donation of $______.
☐ Please charge $______ each month for ____ months for a tax-deductable donation of $______.

Payment (Do not send cash): ☐ Check ☐ Visa ☐ MasterCard
Card #: ____________________________ - ____________ - ____________ - ____________ Expiration Date: ___ / ___

Signature (REQUIRED):

Printed Name: _________________________ Date: __________

Address:___________________________________________

City: _________________________ Tel: __________

State/Province: __________ Postal/Zip: __________ Country: __________

Email: _______________________________________

GIVE THE QUARTERLY AS A GIFT!

Recipient's Name: ___________________________

Address: ___________________________

City: ___________________________ Tel: __________

State/Province: __________ Postal/Zip: __________ Country: __________

www.pemphigus.org Fall 2011
Donate online or download a mail-in form at www.pemphigus.org/donate