BOSTON: HERE WE COME!!

Every year the IPPF hosts an Annual Meeting, bringing together patients and physicians for a weekend of education, friendship, and hope. This year, the IPPF’s Fifteenth Annual Patient/Doctor Meeting takes place May 18-20, 2012 in Boston, MA, at the Hyatt Harborside Hotel.

The 2012 meeting committee has been hard at work since July 2011. This year’s meeting could not be possible without the help of some very special Bostonians: Dr. A. Razzaque Ahmed and Alan Papert (PV) who were both invited to join the Annual Meeting Committee. Since then, they have proven to be invaluable with their knowledge and support in planning the largest and most patient-centered meeting in our history!

This is the first meeting with significant participation by dentists who specialize in Oral Medicine, and it will also be our first to place significant emphasis on pemphigoid (both bullous pemphigoid and mucous membrane pemphigoid). Pemphigoid is far more common than pemphigus and often affects the elderly. Since the population is rapidly growing older, providing more information on pemphigoid is relevant and pertinent. Both pemphigus vulgaris and mucous membrane pemphigoid frequently present first in the mouth, so this is a wonderful opportunity to focus our attention there. For patients who have lost teeth, there will even be a special discussion on the potential role of implants. Lectures and discussion groups led by experts in Oral Medicine will provide information on a wide spectrum of issues that affect the disease, diet and oral hygiene.

This year’s Annual Meeting will

Continued on page 8...
Libraries Are Your Friend

Every now and then the IPPF publishes a document abstract or link to a published report on a site where there is a subscription or a pay-per-download requirement. We have some great news for you: you may be able to get the article for FREE!

The use of public libraries has been declining ever since the explosion of the Internet in the mid-1990s. While almost everything can be found online from the comfort of your home, not everything can be accessed for free. However, thanks to your local library, you can access many of the 24,000 trade journals published from around the world. ... FOR FREE!

Some libraries even allow patrons to access these valuable electronic resources from the comfort of their own home. With a valid library card and online access to your library, you can search for the publication you want to read using your home library account. Each library and website are different so if you get stuck, call or visit your local library where someone will help you get what you are looking for. Some libraries will even print out the article you are looking for if you have the article's title, author, and journal name/volume. And if you are a student, you already have access through your school's online library.

The information is available and yours for the taking. Just ask your librarian. You can also ask our own Library expert at: askthelibrarian@pemphigus.org.
From the Top

Will Zrnchik
Interim Chief Executive Officer
will@pemphigus.org

Spring is in the air and the Annual Meeting is around the corner. Join us in Boston from May 18-20, 2012 for our Fifteenth Annual Patient/Doctor Meeting. The IPPF Annual Meeting Committee has been working since July 2011 to ensure this meeting becomes the benchmark for years to come.

Rare Disease Day (February 29, 2012) was a huge success all over the world and led us straight into National Autoimmune Disease Awareness Month in the United States (March 2012). The American Autoimmune Related Diseases Association (AARDA) estimates there are over 50 million people in the US living with an autoimmune disease. Globally, that number is just as staggering. To make matters worse, not everyone who has an autoimmune disease knows where to go for assistance. The IPPF wants P/P patients to know we are here to help! We are fundraising for Awareness Projects that will inform medical professionals about P/P and the IPPF’s support networks - networks that helps patients around the world each and every day. Help us reach our goal of $31,000 in the 31 days of March by donating today at www.pemphigus.org/donate31. For ways you can help with 3in31 turn to page 5.

Have you signed up for our FREE Health Management Program? Now is the time to do so! The new online management system tracks your progress and provides a growing library of information on Pemphigus, Pemphigoid, treatments, and more! Once you register and complete your initial assessment, you’ll have access to these materials, a Disease Management System, tools, and click on SIGN ME UP! to get started.

I want to thank everyone for supporting the IPPF - the Board of Directors, the Medical Advisory Board, Peer Health Coaches, individual donors, local fundraisers, and support from our online users. Every effort to reach out makes a huge difference in the lives of patients and caregivers around the world.

I hope to see you in Boston!

SPECIAL MEETING PRICING FOR MARCH 2012!
In recognition of National Autoimmune Disease Awareness Month, we are offering a 20% discount of the current Registration Fees of $175 (regular) and $75 (caregiver). Act NOW!
What's in a Name?

by Terry Wolinsky-McDonald, Ph.D.
Licensed Clinical Psychologist &
IPPF Board of Directors

March is National Autoimmune Disease Awareness Month and about 200 of all autoimmune diseases are considered rare diseases. Pemphigus and Pemphigoid are two of these.

How many people do you know who don’t know the difference between AIDS and AID?

Acquired Immune Deficiency (HIV) is well known and feared. After all, it can be “caught” and is “infectious” placing the immune system in a weakened state and unable to defend itself. On the other hand, autoimmune diseases are when the immune system is actually fighting itself. Autoimmune diseases are not infectious or contagious.

It is unfortunate so much confusion exists between the two. Some people do not know AIDS stands for Acquired Immune Deficiency Syndrome while AID is an abbreviation for autoimmune disease.

People with autoimmune diseases are often feared, especially if certain signs and symptoms are clearly evident. Patients can feel like lepers (as if they need this additional stress with everything else going in the body). Sometimes it is difficult to find people who actually understand. Even family and friends have difficulty understanding. Although well-meaning friends and family want to help and be there for you, they may be afraid to visit or fail to read information on the condition. On the positive side, it is a good way to find out who your true friends are and whom you can count on. I have used the following analogy with confused people: "You can catch this from me the same way you can catch arthritis by shaking hands." People seem to understand this concept and can relate to it. It removes the fear aspect.

As I write this, your IPPF Annual Planning Committee is waist-deep in planning a special weekend that will knock your socks off! If you can make it to Boston, May 18-20, 2012, please register soon. This meeting will be phenomenal and history making with Dr. Razzaque Ahmed hosting. The meeting will be truly international with experts from not just North America, but also from Italy, UK and The Netherlands -- and it will be very patient oriented.

You will not regret attending so I encourage you to join us, if not for the entire weekend then for a day. There will be something for everyone, with both large plenary sessions, as well as smaller, more intimate break out sessions. You will have the opportunity for questions to world-renowned experts, and hear the most up-to-date and state of the art information available. The experts are a dedicated group of international clinicians and researchers in pemphigus and pemphigoid who search for better treatments, and eventually a cure.

Remember this March we are all being recognized as part of a larger group. If each of us can just educate one person during this special month we will be providing a special service: the more people who gain understanding, the more we continue to move forward with our mission.

In the spirit of helping others, if you have not participated in our Registry or our FREE Health Management Program, please consider doing so. They are part of our continued effort to have a growing amount of patient (private and confidential) information to show our numbers and learn more. We know there is power in numbers and so much information to collect and use for us and for future generations. And, if you can contribute in other ways, please do. We know that people who help others tend to be happier people.

I am looking forward to our Annual Meeting, seeing old friends and meeting new ones. Be part of a history making event with people who totally understand what you go through on a daily basis. What’s in a name? Let’s make pemphigus and pemphigoid household names! Let’s educate as many people as we can and help everyone along the way.

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.
Let’s Make a Wish Using Causes
Leverage Facebook & Causes to create awareness and fundraise

by Marc Yale
Senior Peer Health Coach

With all the pressures for people to use social networking these days one thing is for certain: either you like Facebook or you don’t!

I have to say that as a Pemphigoid patient, I really like it and have found it instrumental in reaching others who share my condition. Not only do we have the IPPF Forums on our web site, but Facebook provides us with wonderful groups like; PV Friends, Pemphigus Vulgaris, Mucous Membrane Pemphigoid and Fundacion Penfigo to interact with others.

The thing that I have found most useful about Facebook is it has helped me bring attention to the diseases of Pemphigus and Pemphigoid through my connections. That’s right, use Facebook for a good cause! I was able to raise over $800 for my birthday in 2011 that went directly to the IPPF -- by just asking for a simple donation of $10! It made my friends and family aware of my condition and helped the IPPF at the same time!

With National Autoimmune Awareness Month upon us, I have asked all my friends and family to show their support. I am asking them to join my cause and helping me with my “Wish” to support Pemphigus and Pemphigoid Awareness and Research. Please join me and ask your friends and family too! Together we can make a difference!

It’s very easy, Facebook will provide all the tools that you need to spread the word and help you reach your fundraising goal!

Turn to page 10 for steps on how to create a Wish using Causes on Facebook.

You can support the IPPF’s 31in31 during National Autoimmune Disease Awareness Month using the form on page 9 or when you register for the Annual Meeting (page 11 or online).
The story of a Medical Interpreter
Jessica is the first woman in New York State to become a Certified Medical Interpreter. What makes this story more inspiring is she moved to the United States from Puerto Rico at the age of 7 and dropped out of college because PV. In remission for 8 years, Jessica’s story offers hope and encourages others.

Be a Doctor first... then specialize
Dr. Lancer believes in finding what is wrong with the patient and focusing on how to fix the problem. He enjoys his job and he works hard on it. He once said, “When you can’t remember how to diagnose pemphigus, you’ve damaged the specialty. Be a whole doctor first, then specialize.”

Rituximab study: a single center’s observations
Forty-two patients with pemphigus were treated with rituximab and followed up for up to 5 years. No additional immunosuppressive agents were used. Steroids were rapidly tapered. What was uncovered?

The dog ate my homework!
IPPF guest blogger Miki is back and loaded with caffeine. Her latest tales involves medical jargon, a nap, some pretty pictures, and her beloved perspective of the world around her.

The 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
UPDATE: Mucous Membrane Pemphigoid Consensus Meetings
International experts continue to meet and define P/P standards

Doctors Vicky Werth (IPPF MAB Chair) and Dedee Murrell (IPPF MAB) have continued the international collaboration of Autoimmune Blistering Disease (AIBD) experts in order to standardize definitions and measure skin condition scoring. The first successful outcomes was with pemphigus and the results were published in 2008. Bullous pemphigoid (BP) was published online in the Journal of the American Academy of Dermatology (JAAD) in November 2011.

The first mucus membrane pemphigoid (MMP) meeting was held in May 2011 at the World Congress of Dermatology in Seoul, Korea. This event was sponsored by the IPPF and brought together 15 international bullous experts for a two-hour long discussion. Afterwards, they emerged with a draft document of the definitions - and a decision to involve ophthalmologists due to the ocular component.

The second meeting was in October 2011 at the European Academy of Dermatology and Venereology (EADV) in Portugal. This meeting involved 15 more experts from across Europe and the team completed the definitions part of the project. A third meeting will be held at the American Academy of Dermatology in San Diego on Saturday March 17, 2012, and additional updates will follow.

Additional information can be found in the following articles:


What you need for your library (see page 3 for how to use this information)

Title: Consensus statement on definitions of disease endpoints and therapeutic response for pemphigus
Author: Murrell DF
Publication: J Am Acad Dermatol (Journal of the American Academy of Dermatology)
Issue: 58 (June)
Pages: 1043-1046

Title: Definitions and outcome measures for bullous pemphigoid: recommendations by an international panel of experts
Author: Murrell DF
Publication: J Am Acad Dermatol (Journal of the American Academy of Dermatology)
Issue: 66 (March 2012)
Pages: 479-485

Prof. Dedee Murrell is a member of the IPPF Medical Advisory Board, and Head of the Department of Dermatology, St George Hospital, and Professor of Medicine (Conjoint), University of New South Wales.
...continued from BOSTON, page 1

truly be “international.” There are two speakers from the United Kingdom, an expert in Oral Medicine from Italy, and the Director of a Center for Blistering Diseases from the Netherlands. The participants will have the opportunity to discuss how pemphigus and pemphigoid are managed in Europe.

The focus of Day 1 was tailored to address issues of concern and relevance to patients and their caregivers. This will include lectures by experts in oral medicine, ophthalmology, ENT and gastroenterology so patients can see the disease process as it affects these mucosal tissues that are not visible by the naked eye.

There will also be plenty of lectures from dermatologists and other experts concerning issues about the use of corticosteroids (prednisone) -- especially the dose, duration, and side effects. Similarly, there will be a lecture on immunosuppressive agents, focusing on which agent to choose, when to start and what side effects to monitor. Specifically, there will be talks on the use of intravenous immunoglobulin (ivig) and Rituximab. A large panel of topics have been chosen for the discussions during the two breakout sessions.

A much anticipated new session on reimbursement issues will focus on getting approval for therapy as well as payment coverage. A special highlight of the Meeting will be a complimentary “Gala Dinner” with live music on Saturday night for all the registrants. A very special guest speaker is expected to speak at the dinner!

Day 2 will be devoted to scientific issues and presenting cutting-edge research in pemphigus and pemphigoid. Experts will discuss the science behind the diseases, treatments, and a look at what is up and coming in the future.

Boston is a major tourist destination. With so many historical sites, museums, boat tours through the Massachusetts Bay and tours of internationally recognized universities such as Harvard and MIT, we hope you will take advantage of your time there! Participants and caregivers may choose to go to these sites individually or in groups to reduce cost. There will be ample opportunity to meet patients and their caregivers from all over New England and the US as well as a few international participants.

The interest in the Meeting has been enthusiastic. All the rooms at the Hyatt Harborside have been booked for our special conference rate, so we have also negotiated with Embassy Suites Hotel (just a half a mile away) to keep costs down. Embassy Suites will provide transportation on their shuttle to and from our conference site to ease your transition.

Don’t miss this opportunity of a lifetime! Included in the Registration and Caregiver fees is our Friday Night Welcome Reception, breakfast on Saturday and Sunday, lunch on Saturday, a semi-formal sit-down dinner on Saturday night, all session breaks, conference materials, and special gifts from the people of Boston. For more meeting information and updated room rates and locations, please visit us online at www.pemphig.us/2012am.

By all counts, the Boston Meeting will be a memorable one—not to be missed! However, if you can’t make it to Boston, you CAN FOLLOW the meeting on Twitter (www.pemphigus.org/twitter and use hash tag #IPPF12) or Facebook (www.pemphigus.org/facebook). No matter how you join us, the 2012 Annual Meeting will be bigger and better than ever!
**Brunch Brings New York Support Group Together**

by Toby Speed

The sun was shining when our New York area support group met for brunch on December 11th. What a great day! Organized by Matt Koenig, our get-together took place in a lively Greek restaurant called Agora Taverna in Forest Hills, Queens. Six of us came from locations as diverse as Long Island (me), New Jersey, and the boroughs of Queens and Brooklyn. Matt had picked the spot because it was accessible by car, bus and train, which made it easy for this geographically widespread group to meet.

We sat around the table, enjoying omelets and talking nonstop for about two hours. Everyone had a chance to ask questions and compare notes on our histories with pemphigus or pemphigoid. We exchanged ideas, resources, and most importantly a good dose of warm support that is so vital to those making the journey through this disease.

On a personal note, I was very happy to meet others from my area face to face, because my journey up to that point had been a lonely one and I was full of questions. A couple of us who were more recently diagnosed found it encouraging to see how others manage with humor, courage and tenacity for years and even decades. We also talked about future meetings, which will take place in a variety of locations around New York City. We hope to include guest speakers at some of our events.

Everyone in the New York metropolitan area—Manhattan, Brooklyn, Queens, Bronx, Staten Island, Long Island, New Jersey, and Westchester—is welcome to join us at our meetings. **Our next lunch will be on March 25th,** location to be determined.

For more information and to get on our email list, contact Matt Koenig (mattkoe@aol.com) or me, Toby Speed (flygal716@gmail.com).

Some of us are planning to attend the Annual Meeting in Boston this May. I’ll be there for sure. If you are from the New York area and come to Boston, look me up and say hello!
How to Create a Wish on Facebook using Causes
Fundraising just got a whole lot easier when you wish for our cause!

1. Go to our Facebook page at pemphigus.org/facebook.
2. In the menu on the left, click on the 31in31 menu item.
3. Click the link at the bottom of the screen.
5. On “Setting up your Wish” you can dedicate your wish to someone (optional). Select the cause: Support Pemphigus and Pemphigoid Awareness and Research. If you are not already a member of the cause, use the search bar to find it, join and select. Hit Continue!
6. How much should the suggested donation be? Choose an amount (I entered $10). How much money do you want to raise overall? Choose an amount you want your goal to be. Hit Continue!
7. Fill in the blanks! Make it personal so your friends and family know why you are asking for support and why. Click “All Done!”
8. You now have created your “Wish”! Now post it to Facebook. Type a message to family and friends so they will know about your “Wish”. Click “Post to Facebook.”
9. Email your family and friends! You can use your current contacts from your email address books.
10. Tell your Facebook contacts about your “Wish” by sending them a wish invitation!
11. You can create an event so your contacts can see your “wish”.
12. Write a “Wish” status message to remind everyone about your goal!
REGISTRATION FORM

Print Name (as you want it to appear on your name badge)

Organization/Employer Name (Corporate Sponsors Only)

Mailing Address - Street
☐ Home  ☐ Work

City State/Province Zip/Postal Code Country (other than US)

Daytime Phone:  ☐ Home  ☐ Work  ☐ Cell (___)

Email:  ☐ Home  ☐ Work

HOW TO REGISTER

1. Register Online: www.pemphigus.org/annualmeeting
2. Call our offices: (916) 922-1298 x1003
3. Contact your Peer Health Coach
4. Mail this completed form with payment to:
   IPPF AM Registration, 2701 Cottage Way #16, Sacramento CA 95825

Registration cannot be processed without payment. Payment must be in US funds.
All cancellations must be received in writing. For cancellations postmarked on or prior to
April 20, 2012, we will refund registration costs less $25 administrative fee. Cancellations
postmarked between April 20 and May 11, 2012 may be refunded up to 50% of the registration
fees. We may be unable to make refunds after May 11, 2012 due to food, beverage and material
costs. We will gladly transfer your fees to another person as a scholarship, or credit you with a
tax-free donation.

DISEASE INFORMATION

☐ PV  ☐ PF  ☐ PNP  ☐ BP  ☐ CP  ☐ OCP/MMP
☐ Other ____________________
☐ None

Annual Meeting Registration Fees

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<td>Registration Fee</td>
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<td>Includes attendance for all three days, materials, food/beverage during meeting times, Friday’s Welcome Reception, Lunch on Saturday, and Saturday Evening’s Gala Dinner Celebration! Subject to change without notice.</td>
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<td>Caregiver Registration (one may be purchased with each paid Regular Registration)</td>
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<td>*$75 after March 2012 and $100 at the event</td>
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<td>Scholarship Donation. Please help someone else attend this year’s meeting.</td>
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<td>3/13/13 Awareness Month Donation. Support the IPPF’s Awareness Programs!</td>
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<td>Enjoy your National Autoimmune Disease Awareness Month 20% Discount!</td>
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<td>DON’T FORGET YOUR HOTEL! Call the Embassy Suites at (617) 567-5000 and use Group Code IPPF</td>
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Please provide payment if full with your order

☐ Check/Money Order made payable in U.S. funds to IPPF
☐ VISA   ☐ MasterCard

VISA/MC # __ __ __ __ - __ __ __ __ - __ __ __ __ - __ __ __ __
Exp. Date: __ / __
Security Code: __ __ __ __

Billing Address (if different from above): _____________________________________________________

Signature: ________________________________________  Indicates you agree to have your card charged.
BOSTON: 2012

INTERNATIONAL PEMPHIGUS PEMPHIGOID FOUNDATION

Fifteenth Annual Patient-Doctor Meeting

Hyatt Harborside Hotel • May 18-20, 2012

Patient-centered discussions led by the experts
Gala Celebration on Saturday night
Learn about the science and clinical trials
Breakout sessions on topics you care most about
and much, much more!

www.pemphigus.org/annualmeeting