Annual Meeting Exceeds Expectations!
Over 250 attend largest, most informative patient meeting in IPPF history

With the Boston skyline as a backdrop, the IPPF’s 15th Annual Meeting kicked off with more than 100 people gathering for Friday night’s Welcome Reception. The Hyatt Harborside Hotel captivated longtime Boston residents with its beautiful view of Boston Harbor and picturesque city skyline. Guests came from near and far to join in our yearly social gathering of patients, caregivers, and physicians. The room was buzzing with talk of the weekend’s events as people shared their stories among friends.

SATURDAY
Saturday morning began with host Dr. A. Razzaque Ahmed (Director, Center for Blistering Diseases) welcoming everyone to Boston followed by a congratulatory video message from Massachusetts Governor Deval Patrick.

Newly appointed CEO Will Zrnchik welcomed attendees, many of whom came filled with hope for information and answers. He highlighted why people travel from all over the world to be part of these meetings: a common hope | an uncommon bond.

Next, IPPF President Dr. David Sirois (New York University) began with a cheerful welcome and an update on the IPPF. As an ultra-orphan disease support organization, the IPPF “sees its primary mission to connect together the different parts of the community that together can give [patients] a better illness experience.” Dr. Sirois invited attendees to participate in Town Halls, Annual Meetings, the Email Discussion Group, Patient Forums, Facebook, the Pemphigus & Pemphigoid Disease Registry, and IPPF studies and surveys. He then discussed the results of Annual Meeting Exceeds Expectations!

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The IPPF announced its Annual Award winners in Boston during the 2012 Annual Meeting Gala Celebration Dinner. Join us in congratulating this year’s deserving winners!

Vitamin supplements are an important part of a healthy lifestyle when battling chronic health conditions. Also, read how zinc it helps one patient manage his disease - and has for years.

The experts at the 2012 Annual Meeting took time to answer some questions from attendees. Do you have a similar question? The answer you need may be a few pages away.

www.pemphigus.org
Can you believe Summer is here? The days have flown by in a whirlwind of activity here at the Foundation and I would like to take a moment to fill you in on what is in the works.

In case you have not heard, the 2012 Annual Meeting in Boston was a resounding success. It was a true team effort from Planning Day 1 through Sunday’s closing remarks. We ended up with nearly 275 attendees, speakers, and volunteers - more than any other meeting in our history! Attendees included patients in remission for 20+ years, to a patient diagnosed a few days before the meeting started. If you were there, then you already know how incredible this meeting was -- and the fireworks were truly a coincidence! If you were not able to attend, then you missed a doozy, but fear not: everyone can visit www.pemphigus.org/2012am and get copies of the program, presentations, and available audio.

I would like to personally thank everyone who helped make this meeting possible - and the success it was! Turn to page 7 and see who made the 2012 Annual Meeting THE meeting to top! And don’t forget to mark your calendars: the 2013 Annual Meeting will be in San Francisco, April 26-28!

Dr. Terry Wolinsky-McDonald’s "Psychologically Speaking" column will return next issue. If there is a topic you would like her to cover, please email her at terry@pemphigus.org.

As we move into the second half of the year, the IPPF is focusing on increasing physician awareness. Remember when you, or someone you know, was first diagnosed with pemphi-what? Were you one of the lucky ones who was diagnosed in less than a month? Or even less than three? Most are not that lucky. In 2011 the IPPF funded a study to determine how long it takes new patients to be diagnosed. The results indicated patients see an average of 5 doctors over a 10-month span before receiving a proper P/P diagnosis.

This does not have to be! With the right information available to physicians, patients could be diagnosed in days or weeks, not months or years. Our goal is to increase pemphigus and pemphigoid awareness in the medical professions. During March 2012’s National Autoimmune Disease Awareness Month, we raised almost $10,000 towards P/P awareness. In April 2012, the IPPF was awarded a $15,000 grant from the Sy Syms Foundation to help with our Awareness Campaign! And recently, a special donor has pledged even more towards our awareness efforts!

But we are not there yet! Awareness campaigns DO work! To get the most coverage among dermatologists, dentists, and other specialties, we need your help! This summer we are asking everyone to consider a tax-free contribution specifically for our Awareness Campaign.

You can donate online at www.pemphigus.org/donate, call our offices at (916) 922-1298 ext 1003, or mail in the form located inside the back cover. Please consider asking a friend or family member to support this very important effort. And don’t forget about Matching Gifts from your employer! Contact your Human Resources department for more information.

The sooner we can fund this project, the sooner we can increase physician awareness -- and the sooner pemphigus and pemphigoid patients will be diagnosed and treated. That means patients can begin their journey to recovery and remission sooner than ever before!

Finally, thank you for your continued support and have a safe and happy Summer!!
The more data we can collect, the better the information we can give to researchers. Armed with this information, we look forward to better treatments, earlier diagnosis, and one day – A CURE!!

The Pemphigus-Pemphigoid Registry is designed to help the medical and research community understand illness trends, treatment outcomes, disease burden, and some important demographic information about patient(s) age and gender. With this vital information from large numbers of participants we can better advocate for resources to improve patient support and doctor education, and accelerate research discovery.
Every year at our Annual Meeting, the IPPF recognized the “stars” that shine brightest throughout our patient community over the past year. These awards recognize the dedication and support that helped further the IPPF and our mission. The awards for education, outreach, and patient support not only echo the mission of the IPPF, but stand as the guiding principles for our organization and all who support it.

**Education:** Matt Koenig, New York. Matt revived the New York Support Group and utilized the power of social media to bring together pemphigus and pemphigoid patients, not only from the Tri-State area, but from around the world. The Facebook Group, PV Friends, continues to grow and currently has over 60 followers who share their wisdom, stories, and support for one another.

**Outreach:** Dan Goodwill, Toronto, ON, Canada. Dan is a long-standing member of the IPPF Board of Directors. He also led the Toronto Support Group for nearly a decade, and currently is the Chairman of the Canadian Pemphigus & Pemphigoid Foundation’s Board of Directors. Dan was there when the CPPF got its start in 2007, and most recently helped raise over $22,000 as a member of Toronto’s “Pemphigus Pathfinders” during the Scotiabank Charity Run in October 2011.

**Patient Support:** The Blistering Disease Support Group of Boston. This year marks the first year an organization or group has been recognized by the IPPF. The BDSG has been meeting for 23 consecutive years and typically has over 100 people attend for a day of support and sharing. One of the crowning achievements for the BDSG is that members come year after year regardless of their disease state to offer hope and inspiration to others. Present at the 2012 Annual Meeting were 123 patients and caregivers from the BDSG - 49 of them in long-term remission. It is only fitting the BDSG was recognized for its 23rd annual meeting at the IPPF’s 15th Annual Meeting.

*The IPPF would like to congratulate all our Star Award winners!*

The **Founder’s Award** is given in recognition of an individual’s extraordinary contributions to the growth and future of the IPPF, much like those of IPPF Founder, Ms. Janet Segall. The Founder’s Award goes to people who have dedicated their life to helping pemphigus and pemphigoid patients. Janet was committed to more than the growth of the Foundation, but with how patients were actually treated, seen, and cared for. Janet often went above and beyond expectations to help a fellow patient without expecting a donation or a thank you. She did it because she loved helping others overcome their struggle with pemphigus and pemphigoid. Therefore, the recipient of the Founder’s Award is more than dedicated and passionate - their name is synonymous with the IPPF and its mission and values.

This year’s recipient was **Mindy Unger**.

Mindy is a member of the IPPF Board of Directors where she is the Chair of the IPPF Fundraising Committee. Mindy’s dedication and contributions to the IPPF have allowed the Foundation to continue on the path Janet Segall began in 1994. Her leadership, commitment, and dedication have laid the foundation for years to come, and serve as a constant reminder that one person can make a difference, much like Janet did, not for recognition, but because it is the right thing to do.

*Congratulations Mindy, and thank you for all you do.*

The **IPPF Doctor of the Year Award** recognizes research and support that has bettered the lives of pemphigus and pemphigoid patients around the world during the previous year. This year’s Doctor of the Year Award recipient was **Dr. Razzaque Ahmed**.

Continued on page 5...
After a standing ovation with cheers likely heard on the other side of the Harbor, Dr. Paul Konowitz presented the award to a very surprised and humbled Dr. Ahmed. Dr. Konowitz is a Director on the IPPF Board of Directors, a Boston ENT specialist, and friend and patient of Dr. Ahmed.

Dr. Ahmed is the Director of the Center for Blistering Diseases in Boston, the first facility of its kind in the United States. In May 2011, he received the Lifetime Achievement Award from the Pan Arab League of Dermatologists, where His Royal Highness, the Crown Prince of Dubai himself presided over the session.

Dr. Ahmed’s quest to better the lives of pemphigus and pemphigoid patients around the world — through science and practice — have made a deep and lasting impact on the world of orphan diseases.

**Congratulations Dr. Ahmed, and to all of our 2012 Annual Award winners!**

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**KabaFusion CEO Honored by IPPF and Center for Blistering Diseases**

Dr. Sohail Masood, Founder and CEO of KabaFusion (2012 Annual Meeting Platinum Sponsor) was recognized by the IPPF and his longtime friend, Dr. A. Razzaque Ahmed.

Dr. Masood was given a beautiful marble plaque honoring him and his personal contributions to the success of the IPPF 2012 Annual Meeting, as well as a career dedicated to providing patients with affordable care. The plaque was presented by Dr. Ahmed, Dr. David Sirois (IPPF President), and Mr. Will Zrnchik (IPPF CEO).

Thank you, Dr. Masood, for all you have done -- and continue to do -- for patients around the world.

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"Thank you Dr. Ahmed and IPPF for your hard work and dedication in organizing an AMAZING Patient-Doctor meeting in Boston! This was the first time I attended the IPPF Annual Meeting and I was excited to be part of it. The resources made available to the pemphigus community were invaluable and contributed to the success of the meeting - the doctor presentations, the plenary and breakout sessions, as well as time to meet and connect with other pemphigus patients from around the country. Participating in the meeting reaffirmed my belief in how fortunate we are to have the IPPF’s services and support at our disposal, especially those who do not have access to dermatologists familiar with this rare disease. Thank you IPPF Staff and Coaches, the Board of Directors and Medical Advisory Board!"

~Ellen
People with chronic health conditions like pemphigus and pemphigoid are more likely to have vitamin and mineral deficiencies. These deficiencies can be from the disease itself, the regimen of medications, or the change in lifestyle after being diagnosed.

Our bodies absorb vitamins and minerals from the foods that we eat, and often our diets change dramatically after being diagnosed with pemphigus and pemphigoid. If there is oral involvement, patients often choose foods that are easy to digest and swallow.

The following is a discussion on some of the most important vitamin and minerals needed for pemphigus and pemphigoid patients. Vitamin and mineral supplementation is very important to keep your body operating properly.

- **Vitamin D**: One of the most important vitamins needed for pemphigus and pemphigoid patients because the combination of lack of sun, prednisone, and the disease itself can deplete the body’s absorption of this vitamin.

- **Calcium**: If you are taking prednisone, ask your physician about a calcium supplement. Osteopenia and Osteoporosis are common.

- **Iron**: Fatigue is a direct result of pemphigus and pemphigoid, and can also be caused by lack of iron in our diets. Some medications (dapsone) used to treat your condition can also cause anemia, or lack of iron in your blood.

Here are other vitamins and their uses that may be helpful. Make sure you ask your physician about:

- **Vitamin A (retinol)**: The body uses vitamin A to form and maintain teeth, mucous membranes, skin, and hard and soft muscle tissue.

- **Vitamin B3 (niacin or niacinamide)**: Reduces low-density lipoproteins, or bad cholesterol and fibrinogen, which may contribute to inflammation.

- **Vitamin B7 (biotin)**: Supports healthy hair and skin by helping process proteins.

- **Vitamin B9 (folate or folic acid)**: Helps with anemia, especially in patients taking methotrexate.

- **Vitamin B12 (cobalamin)**: Helps maintain healthy nerve cells and red blood cells.

- **Vitamin C (ascorbic acid)**: Used for iron absorption and collagen, bone, cartilage, muscle and blood vessel formation.

- **Vitamin E (tocopherol)**: Substances that damage cells by stealing electrons and destroying cellular DNA. Exposure to environmental toxins such as sunlight and tobacco smoke may trigger free-radical formation in the body. The body also uses it to form red blood cells and absorb vitamin K.

- **Vitamin K (phytonadione)**: The body stores it in fatty body tissues. Clinicians may use it to control the effects of anti-coagulant medication. It also supports healthy bone structure.

- **Zinc**: Regulates protein synthesis, growth development, and wound healing. (*See related story, page 11*)

- **Magnesium**: Involved in cellular energy production, bone structure, and nerve and muscle function.

These are just some of the vitamins and minerals that can help you manage your condition. It takes a multifaceted approach to improving your condition, and supplements might only be a part of the solution. Please check with your physician regarding these vitamins and minerals and the amounts that they recommend before using them.

When you need us, we are in your corner! Please visit [www.pemphigus.org/coachescorner](http://www.pemphigus.org/coachescorner) for informative articles from your IPPF Peer Health Coaches. If you are interested in becoming a Peer Health Coach, email Marc at [marc@pemphigus.org](mailto:marc@pemphigus.org), or call (916) 922-1298, ext. 1006.
Thank You Boston!

It took dozens of volunteers working months to ensure success

The 2012 Annual Meeting is in the books - the record books that is! The 15th Annual Meeting surpassed all previous records for the IPPF: attendance, sponsorships, speakers, excitement, entertainment, and more!

A very special THANK YOU goes out to the IPPF’s Annual Meeting Committee. Co-chairs Dr. Terry Wolinsky-McDonald and Will Zrnchik, Sonia Tramel, J. Gregory Wright, and Marc Yale were joined by Dr. A. Razzaque Ahmed and Mr. Alan Papert, both from Boston. The committee started planning the Boston meeting in July 2011 and the results were amazing.

The 2012 Annual Meeting would not have been possible were it not for the generosity of our sponsors and volunteers. Our Platinum Sponsor was KabaFusion (www.kabafusion.com). Dr. Sohail Masood and his team did everything from helping with registration and handing out awesome gift bags full of swag, to answering patient questions and greeting arriving guests at Saturday evening’s Gala Celebration. The IPPF is pleased to welcome KabaFusion as a partner and we look forward to continued success.

Our Gold Sponsor, AxelaCare (www.axelacare.com), has been a sponsor since 2009 and Mr. Brian Cleary has helped many pemphigus and pemphigoid patients with insurance-related issues.

Our Silver Sponsors were Crescent Healthcare, Inc. (www.crescenthealthcare.com), PNC Wealth Management (www.pnc.com), and NuFactor Specialty Pharmacy (www.nufactor.com). Crescent has been an IPPF sponsor since our 2006 Annual Meeting in New York. Both PNC and NuFactor are new sponsors and the IPPF welcomes them to our family.

Our Bronze Sponsors were BIOFUSION (www.biofusion.com), Centric Health Resources (www.centrichealthresources.com), and the Massachusetts Eye Research and Surgery Institution (MERSI, www.mersi.com). Biofusion first sponsored the IPPF back in 2003 and has been a valued partner ever since. Centric has been a sponsor since 2006 and helped develop the free IPPF Health Management Program (www.pemphigus.org/hmp). The IPPF welcomes MERSI as a sponsor this year and looks forward to the future.

The Blistering Disease Support Group from Boston contributed hundreds of hours of work to help with planning, dinner, and entertainment arrangements; packaging thousands of product samples; and greeting attendees to the meeting. A special thanks goes out to the Stillman’s and Peckrill’s for their leadership of this massive project. The Boston Support Group, led by Alan Papert, helped with site surveys, event planning and A/V coordination. Alan’s wife, Gloria Papert, was her usual self helping with the registration table, answering attendee questions, and making the event an enjoyable one for everyone. Thank you, Alan and Gloria, for your support.

Bruce Heath, Vicki Garrison, Phyllis MacPherson, Dr. Shawn Shetty, and Dr. Marsha Fearing from Dr. Ahmed’s office helped with everything from sending letters and flyers, to attendee and speaker reservations and registration. And the muscle behind the event, Ike Mahmood and Ghulam Ali, helped package, load and transport over 2,000 pounds of donated products.

Lastly, Kendra Smith, Convention Services Manager at the Hyatt Harborside, worked with the IPPF Annual Meeting Committee to make the impossible possible.

Thank you everyone for making this THE meeting that has raised the bar to a new level. The IPPF invites this year’s attendees, and the entire pemphigus and pemphigoid community, to join us April 26-28, 2013, in San Francisco for the 2013 Annual Meeting (information will be sent out later this year).

2012AM by the Numbers

People in Attendance: 271
Patients: 119
Caregivers: 78
Patients in remission >5 years: 49
Product Samples: $21,000 (over one ton of lotions, shampoos, and more)
Speakers: 21 from 6 states and 4 countries, including 7 dentists
Lunch: 253
Dinner: 247
a recent IPPF study that showed delays for initial diagnosis, including a patient seeing five physicians over a 10-month period. Dr. Sirois also discussed the cornerstone of the IPPF’s 2012 efforts: the IPPF Awareness Campaign. This program will focus on physicians in training and in practice to increase recognition of these diseases, provide guidelines for treatment and care, and bring new clinicians into medical dermatology committed to bullous diseases through fellowships and scholarships.

The opening talk was given by Dr. Grant Anhalt (Johns Hopkins University), who provided a brief overview on pemphigus and pemphigoid. Dr. Anhalt was instrumental in helping Janet Segall found the National Pemphigus Vulgaris Foundation in 1994 (today known as the International Pemphigus Pemphigoid Foundation). Dr. Anhalt’s discussion covered how the immune system uses antibodies against antigens. He also mentioned that autoimmune diseases are the third most common group of diseases behind cardiovascular diseases and cancer. Dr. Anhalt mentioned how none of the drugs used to treat the disease can be used to treat the target area, but must focus on getting rid of the antibody produced by the immune system.

Next, legendary pemphigus and pemphigoid physician Dr. Samuel Moschella (Lahey Clinic Medical Center) told attendees what it was like to treat pemphigus before prednisone was available. His stories of varying treatments and therapies of pemphigus vulgaris malignus were met with silence as he mentioned “70-90% of these patients died from this disease” as a result of infection, malnutrition, or other electrolyte and protein problems, and how it was treated much like burn victims. As Dr. Moschella’s story moved along his timeline, the introduction of better therapies and an increased understanding by physicians improved treatment.

The first dental talk of the day was given by Dr. Sadr Kabani (STRATA Oral Pathology Services) on the oral manifestations of pemphigus. Dr. Kabani mentioned pemphigus may begin with canker sore-like lesions on a localized area of the gums or inside of the cheek, that can become progressively worse. A common site of involvement is the soft palate. Gum involvement is common and might be the only manifestation. Diagnosis is based mostly on clinical presentation, but must be confirmed by a biopsy and immunoflorescence.

Dr. Sook-Bin Woo (Harvard Dental School) discussed the clinical presentation and diagnosis of pemphigoid in the oral cavity. Dr. Woo opened with how pemphigoid is often associated with eye and skin lesions, but more often than not it is associated with purely the oral region, and typically female. She mentioned that blisters are not commonly visible because they rupture frequently, so peeling mucous membranes are a good indication. Dr. Woo said a biopsy is a must in

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Speaker presentations and audio from the Plenary Sessions are available online at www.pemphigus.org/2012am. Also, the process of transcribing the plenary sessions is almost done! Transcriptions, as they are finished, will be available in the download package for each presentation (audio, presentation slides, and type transcripts).
properly diagnosing pemphigoid in the mouth. She said 95% of her patients are oral only without skin or eye involvement, but does not rule those areas out until after the patient sees a dermatologist and ophthalmologist.

Attendees were then free to attend one of seven breakout sessions, or workshops. The morning’s sessions focused on oral issues, topical management, and coping with pemphigoid. Afterwards, everyone enjoyed a scenic luncheon outdoors in the Grand Pavilion before returning for an afternoon of systemic information.

Dr. Kunal Jajoo (Brigham and Women’s Hospital) began with a talk on esophageal involvement of pemphigus and pemphigoid. The diagnosis of esophageal involvement involves radiology and endoscopy. In the majority of patients he cares for, the primary disease has been diagnosed, so he focuses on if there is esophageal involvement using tests like the Barium Swallow (a patient drinks a chalky milk-like substance comprised of a metallic compound that shows up on x-ray). He also mentioned careful consideration must be given before biopsying the esophagus so not to cause further damage, unless the diagnosis is uncertain or the results will change disease management.

Next was a presentation on ocular involvement by internationally recognized eye specialist Dr. C. Stephen Foster (Massachusetts Eye Research and Surgery Institute (MERSI) and Harvard Medical School). He gave a basic overview of the eye, and how the bulk of the ocular area is not affected by the blistering, but how it is focused on conjunctiva (the lining of the eyelids and the whites of the eye) and the cornea itself. Unlike the skin, the eye is very unforgiving of chronic inflammation and, therefore, therapy should be aggressive for MMP patients with eye involvement.

Vice Chair of the IPPF Medical Advisory Board Dr. Sergei Grando (University of California - Irvine) spoke about systemic corticosteroids and if they are “friends or foe.” It is important to learn that prednisone can be your friend. It has reduced the mortality rate of pemphigus to 5-12% when used with a steroid sparing agent/regimen such as cytotoxic drugs, protein inhibitors, or IVIg. Dr. Grando pointed out that prednisone mimics the body’s production of cortisol acetate (the adrenal gland produces 35-40 mg/day, which is equal to 7-8 mg of prednisone). However, when doses are too high or too low, or non-responsiveness is not recognized, systemic corticosteroids can become a foe. This can lead to enhanced appetite, fluid and salt retention, emotional disorders, diabetes, hypertension, and more.

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Adding Zinc to Your Diet
by Skip Van Lenten
pemphinremission.com

People have been asking how to go about adding zinc to their diet. It is very simple. Although many doctors are beginning to suggest that their patients add a multivitamin to their diet, most only contain between 11 and 15 mg of zinc, and since prednisone destroys zinc, this is probably not enough to make much of a difference to someone with pemphigus.

There are some newer products on the market (One-a-Day brand has a "50 Plus Advantage" multivitamin for both men and women) that contain either 23.5 or 23.9 mg of zinc. This is the level which seems to have helped some pemphigus patients, and those who have gone into remission did so within three to six months by taking a common "stress tab." Almost all stress tabs contain between 22-25 mg of zinc and can be found in any pharmacy or health food store.

Taking a multivitamin or a stress tab is not intended to be a substitute for the medications used to treat pemphigus. It is a way of improving your general health and you should always inform your doctor if you plan to add one to your diet.

Are you in remission? Please tell your story at www.pemphinremission.com and help others find hope and inspiration!
Our first international plenary speaker was Dr. Richard Groves (St. John’s Institute of Dermatology, London). He presented on immunosuppressive agents, and when a physician should choose which one when treating pemphigus and pemphigoid. Dr. Groves said the aim of adjuvant immunosuppression is to achieve great disease control with minimal adverse effects. These steroid sparing agents include azathioprine, mycophenolate mofetil, cyclophosphamide, sulfa drugs, and tetracyclines, among others. Dr. Groves continued with a detailed discussion on effective options, treatment based on the diagnosis and severity, genetics, and how adverse effects are well understood and controllable.

Dr. A. Razzaque Ahmed (Center for Blistering Diseases) returned to the stage to discuss IVIg and rituximab use in autoimmune blistering diseases. These treatments are an area of controversy and lack uniformity of opinion and therapy. Dr. Ahmed talked about the IVIg treatment protocol developed by 35 experts from the US, Canada, and Europe (published in 2003). He stressed with IVIg “there is an endpoint to the therapy...there is light at the end of the tunnel.” Dr. Ahmed stated IVIg and rituximab, alone or in combination, have shown significant benefit and newer diseases’ specific biological agents will be discovered once there is a better understanding of the pathogenesis of blistering diseases.

Next began the afternoon breakout session (workshops) focused on side effects, ocular pemphigoid, IVIg, genetics, treating blistering diseases differently, and coping with pemphigus. This was followed by a short question-and-answer session with the day’s speakers (see page 14 for some of the questions).

SUNDAY

Sunday brought out the scientist in everyone as the speakers discussed updates, advances, and new therapies.

Opening the day was IPPF Medical Advisory Board Chair Dr. Victoria Werth (University of Pennsylvania) providing an update on the classification of pemphigoid. Since pemphigoid is a sub-epidermal blistering disease, there is a need for standard terminology and severity measures. Based on the number of studies and lack of uniformity among terminology, it is nearly impossible to compare therapeutic outcomes using simple meta-analysis. Currently, several bullous disease experts are working on a Bullous Pemphigoid Disease Area Index (BPDAI) to standardize scoring and terminology, thus making it easier for scientists, researchers, and clinicians to share information. However, further studies are needed to validate this information, as well as validation of eye and ENT scores.

Next, Dr. Ahmed introduced Dr. Grant Anhalt as the “Grandfather of Paraneoplastic Pemphigus,” a title unofficially bestowed upon him since he was one of the first to describe it in 1990. During his talk on PNP, and using several index cases, Dr. Anhalt discussed the history, exam, and treatment plans needed to help the patients. He said most PNP cases are misdiagnosed as chronic erythema multiforme, toxic epidermal necrolysis, and combined lichen planus - and he estimates as many as 75% of cases are still not properly recognized or diagnosed. Dr. Anhalt then discussed why PNP looks and acts differently than pemphigus vulgaris, and how the mortality rate is nearing 90% because it is the most treatment-resistant disease.

Dr. Peter Marinkovich (Stanford University) discussed laminins in skin diseases. Dr. Marinkovich noted that Laminin-332 is absent in a severe, inherited blistering disease. Laminin-332 is an important adhesion molecule and targeting the entire protein would cause widespread blistering. Therefore, selectively targeting Laminin-332’s carcinoma promoting regions does not interfere with tissue adhesion.

Dr. Marcel Jonkman (University of Groningen, The Netherlands) presented on the pathogenesis of bullous pemphigoid. While pemphigus has documented findings dating back to 1768, pemphigoid was not independently distinguished until the early 1950s. Dr. Jonkman discussed the histopathology, diagnostic algorithm, and autoantigens of BP. He also mentioned the role of IgE and how it is faintly detectable in the epidermal basement membrane zone (BMZ) of a BP patient.

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but strongly detectable in the BMZ of a skin organ culture.

Our last international speaker was Dr. Michele Mignogna (University of Naples, Italy) who presented on his 20+ years of treating patients with oral pemphigus and pemphigoid in Naples. Dr. Mignogna has used a blend of conventional methods and newer strategies. He talked about the differences between treating patients in the United States vs. Italy. Generally, Dr. Mignogna prefers to use rituximab (and IVIg in severe cases) where they can only be used in medical facilities. He then mentioned that the use of rituximab and IVIg do not require insurance company approval in Italy, but the approval of the hospital committee, and are no cost to patients.

Our final speaker of the conference was Dr. Sergei Grando, who returned to the podium to discuss new immunosuppressive drugs for blistering diseases. Dr. Grando discussed the therapeutic ladder for PV and the treatment algorithm for pemphigoid before moving on to cytotoxic drugs. He referenced a study that concluded the “most efficacious cytotoxic drug to reduce steroids was found to be azathioprine.” He mentioned that all treatments have side effects, some of which can be serious, and treatments that work rapidly have the most serious side effects. Dr. Grando discussed the current challenges and said that current drugs suppress all immune responses—good and bad—resulting in unnecessary side effects. Ideally, selective immunosuppressive treatments that could suppress only pathogenic responses would be developed.

This year’s Annual Meeting would not have been the success it was without the presenters who volunteered their time. The IPPF would like to thank each and every speaker for helping make this year’s meeting the best ever!

If you attended the 2012 Annual Meeting as a patient, caregiver, friend, speaker, or sponsor, please complete our online Post-Meeting Survey at pemphig.us/2012am-feedback. Your input will help drive changes to the 2013 Annual Meeting in San Francisco, April 26-28, 2013.
Q: Where do pemphigus/pemphigoid scientists get funding for research, and are they indebted to the funder?

A: Some researchers are funded by NIAMS (National Institute of Arthritis and Musculoskeletal and Skin Diseases, a department of the NIH). Pemphigus funding seems to be higher than other orphan diseases. Two groups have focused on desmogleins 1 and 3 as a cause of pemphigus. The NIH has supported this research totalling between $7-10 million. Since more research has been done highlighting other possibilities, there is hope NIAMS will look at other causes and diversify funding for other mechanisms.

Also, pharmaceutical companies fund some research, but this tends to occur only in profitable disease models (which at this time pemphigus and pemphigoid are not). Because of this, federal assistance is needed for funding and to avoid constraints, obligations, and conflicts of interest. Finally, collaborative studies on pemphigus and pemphigoid (like those in Europe and Japan) should be considered by US-based researchers, which may require revised funding requirements.

Q: What has been learned from other diseases that can be applied to pemphigus and pemphigoid?

A: One example is when rituximab was used to treat a patient with an underlying lymphoma and led to improvements in P/P. The same thing happened when a patient with bowel disease was treated with remicade and their psoriasis improved.

Q: Who discovered that sulfasalazine was helpful for pemphigoid patients?

A: Sulfasalazine is used to treat rheumatoid arthritis, bowel inflammation, diarrhea (stool frequency), rectal bleeding, and abdominal pain in patients with ulcerative colitis. It is one of the first products broken down by the liver and is manufactured on an “as needed” basis. It has been used in place of dapsone to treat bullos pemphigoid and other IGA disorders. Dapsone is Germany’s first-line therapy for BP; France uses methotrexate or clobetasol; Italy uses sulfasalazine. While used in limited instances in the U.S., sulfasalazine is a viable BP treatment, for those who do not respond to treatments such as dapsone.

Q: Can research on hair loss (alopecia) help with hair loss due to pemphigus?

A: Research has shown the protein works in the early antigen phase to drive follicle elongation. However, this requires additional testing.

Q: Because health care systems vary in different countries, and even states, what options do physicians and patients have?

A: Regardless of the best treatment protocol, governments must consider the care of its population as a whole. Therefore, expensive treatments may be delayed so less expensive, but still successful therapies, can be used to treat a larger number of patients. Of course physicians want the best treatments available for their patients, but sometimes funding limitations prevent the use of expensive treatments except in extreme circumstances.
It takes THIS many physicians 10 MONTHS to diagnose pemphigus & pemphigoid.

Why?

Many physicians patients see do not know enough about pemphigus and pemphigoid to make a timely and accurate diagnosis. Diagnostic delays cost patients valuable time and money -- and unnecessary pain and suffering. We must put an end to this!

**PHYSICIAN AWARENESS BEGINS NOW!**

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