Attendees of the 2011 Annual Meeting Saturday Evening Mixer, sponsored by AxelaCare, enjoyed special Motown star-treatment at one of the Motor City’s premiere hot-spots: the Amnesia Lounge. Scott and Rebecca (IPPF Board Member) pose for a picture with the IPPF logo prominently displayed on a giant screen over looking the dance floor. Behind them, attendees who traveled all the way from Denmark, enjoy a chat with Mindy (IPPF Board Member) and another guest.
Well it has been a whirlwind Spring, which in California anyway has seemed to go on and on!

Now that we’ve had a minute to catch our breaths (aside from wrapping up this issue of the newsletter) I want to give a huge shout out to Will Zrnchik, and ask all of you to do the same whenever you get the chance. Will is the person that handles every little detail so that the big picture is perfect. On the front page you will notice the IPPF logo on the tv screens in the Amnesia Lounge - Will. And that there was a picture of it for the front cover - Will. And that there was a front cover of the Newsletter, itself, with the pictures of the tvs ... - Will. And so many thousands of details that make everything run perfectly -- at least after he gives it a talking to!

I stand on the stage and hand out awards, but Will’s work helps someone every day. Thank you for a fantastic meeting, Will, I especially heard kudos about the wonderful food! And thank you to all the sponsors of the meeting, you feel like old friends now, sharing patient’s and the Foundation’s progress from tears to triumphs - you help us provide peer coaches, get doctors to patients, and change the scenery for a chance at better medicines.

For the remainder of the 2011 year our key priorities are an awareness campaign, exploring where/how patients get misguided on their path to diagnosis, and where we can target educational materials that will have an impact on front-line doctors who see the "yet-to-be" diagnosed before something goes awry or someone waits too long.

We are also now collecting and doing a meta-analysis of the current science research on P/P, worldwide (following from the presentations at the 2010 Science Meeting) and will use those, plus our Registry data (over 500 folks now!) to ask expert P/P physicians to develop a "best-practices" plan to guide doctors who are not experts on P/P.

As you will read throughout this issue, the Power of One has moved the cause of P/P care forward tremendously this year. If you have a special talent, please consider putting it to work -- there are so few of us who are so passionately impacted. And if you can, please give financially. Less than 10% of the people who receive direct services from the IPPF turn around to contribute for the benefit of those that follow. Let’s be sure that new folks don’t have to struggle as you might have.

Warmly,

Molly Stuart, JD
Chief Executive Officer
molly@pemphigus.org
The 2011 Annual Patient/Doctor Meeting has come to an end and the message was clear throughout the event: one person can make a difference. The Power of One has grown from a simple catchphrase to a full-fledged movement within the IPPF. Patients shared stories on how they were inspired to do something. Doctors talked about how much education one person can bring to a class of young physicians. Researchers were confident that one person’s participation in a clinical trial or the IPPF Registry could open new doors to progress. The Power of One truly can make a difference.

Each year the IPPF travels to a different location to bring some of the world’s leading P/P physicians and researchers together with patients and caregivers for a weekend of disease education and fellowship.

This year’s event was held May 20-22, 2011 at the MotorCity Casino and Hotel in Detroit, Michigan. Events such as this would not be possible without the support of our partners and the IPPF is proud to have this year’s Annual Meeting sponsored by AxelaCare, Crescent Healthcare, Centric Health Resources, and BIOFUSION. Product samples were also provided by Alwyn Cream.

Before the first presentation was given, members of the IPPF Board of Directors, staff, and Peer Health Coaches met for updates, training, and team building. Friday evening’s Welcome Reception culminated with a drawing for three sets of tickets to see Bill Cosby perform live. The winners were Peggy Linaras, Alan Papert, and Scott Oling. Congratulations to each of you!

Saturday was filled with presentations, breakout sessions, and Q&A with the experts. The event started with a welcome from Dr. Dave Sirois (President, IPPF Board of Directors and Medical Advisory Board member) and Molly Stuart (CEO of the IPPF). Afterwards, Dr. Animesh Sinha opened the first plenary session, Biological and Clinical Aspects of Disease. This session focused on the science of P/P and was designed to help build a basic foundation for patients and caregivers to build on during the meeting.

Dr. Sinha introduced long-time Annual Meeting presenter Dr. Grant Anhalt with an Introduction to Blistering Disorders. He takes the dynamics of the disease and breaks it down into simple to understand terms.

Next, Dr. Sinha took the scientific approach and presented on the Genetics and Immunology of Pemphigus. Dr. Sinha focused on how scientists and researchers look at the basic composition of pemphigus and pemphigoid at the cellular level. Joining Dr. Sinha was his wife, Dr. Kristina Seifert-Sinha and a team of medi-
The AM Who's Who
Our 2011 Annual Meeting Speakers

Thank you to our invited speakers for taking time out of their schedules to not only present, but for sitting down and talking with the patients and their caregivers throughout the Annual Meeting.

A. Razzaque Ahmed, MD
Center for Blistering Diseases
Boston, MA

Grant J. Anhalt, MD
John-Hopkins University
Baltimore, MD

David Fivenson, MD
Fivenson Dermatology
Ann Arbor, MI

Stephen Foster, MD
Harvard Medical School
Massachusetts Eye Research & Surgery Institution
Cambridge, MA

Neil Korman, MD, PhD
Case Western Reserve University
University Hospitals of Cleveland
Veterans Administration Hospital
Cleveland, OH

Animesh A. Sinha, MD
State University of New York and Roswell Park Cancer Institute
Buffalo, NY

David A. Sirois, DMD, PhD
New York University College of Dentistry
New York, NY

Victoria Werth, MD
University of Pennsylvania
Philadelphia, PA

...continued from ANNUAL MEETING, page 3

cal students from Michigan State University. Dr. Sinha's team conducted a blood draw for patients and their families to help with his research.

Rounding out the opening session was Dr. Neil Korman and the Clinical Variation and Course in P/P. Dr. Korman enlightened attendees on the different aspects of the diseases and the need for specialists to focus on these diseases to reduce diagnosis times and increase the quality of care. He also mentioned that it seems fewer medical students are entering the P/P field (bullous and blistering disorders) while many of the "old guard" are approaching retirement. This point helped drive home how one person might be able to persuade one student to focus on P/P who one day may find a cure. Yes, The Power of One.

Groups then split into small breakouts. Dr. Sirois led an informal discussion on the Oral and Dental aspects of P/P. This session covered everything from early signs to safe and effective flossing techniques. Dr. David Fivenson led a session on Bullous Pemphigoid, the first truly pemphigoid-specific session at one of the Annual Meetings. Dr. Fivenson talked about the variations of pemphigoid, clinical presentation, treatment, and individual care. Dr. Stephen Foster’s session on Ophthalmic Disease covered how P/P affect the eyes and offered attendees helpful information they can use themselves and share with their treating physicians.

The Awards Luncheon’s keynote speaker was Rebecca Strong. Her talk, titled The Power of One, shared how she took the words of Dr. David Sirois at the 2010 Annual Meeting: patients need to be the ones to educate others about P/P - including educating doctors. In February 2011, Rebecca did just that. Rebecca shared her story with 212 dental students at the University of Michigan’s School of Dentistry explaining her P/P journey from a lengthy diagnosis to the effects it has on her life. Rebecca felt her reward came when the UoFm students laughed, cried, and asked question after question.

Continued on page 5...
...continued from ANNUAL MEETING, page 4

about P/P and her experiences.

Her presentation kept the audience laughing, crying, and inspired to keep the patient in mind and search for a cure. Rebecca left the stage to a standing ovation.

Rebecca has now become a P/P champion and has offered to help anyone who wants to learn more about talking to others. Ask her how you can help by emailing her at becky@pemphigus.org.

Over dessert, CEO Molly Stuart took time to recognize those who have contributed to the IPPF Community during the past year during the IPPF Annual Awards Ceremony.

The IPPF STAR Award for Education went to Rebecca Strong for educating future dentists. The IPPF STAR Award for Outreach went to Peer Health Coach Susan Gonzales-Thomas for voluntarily staffing an IPPF booth at several local events in her hometown. Susan not only spread the word on pemphigus and pemphigoid, but made contact with a couple of patients, and raised funds to support the Foundation’s programs.

The IPPF Doctor of the Year Award recognizes research and treatment that has bettered the lives of pemphigus and pemphigoid patients around the world during the previous year.

The 2010 Doctor of the Year was Dr. Sergei Grando. Dr. Grando is a Professor of Dermatology and Biological Chemistry at the University of California—Irvine, and Vice Chair of the IPPF Medical Advisory Board. Dr. Grando played an instrumental role in putting together the most influential and forward-reaching pemphigus and pemphigoid scientific meeting in history, the 2010 JC Bystryn Pemphigus & Pemphigoid Science Meeting: From the Bench to the Bedside. Over 130 scientists, researchers, and physicians from around the world participated in discussions on new and emerging findings, treatments, and possibilities.

The results of this meeting were recently published in the Journal of Investigative Dermatology. This meeting will serve as the foundation for several future meetings that will reshape the face of P/P research and treatment.

The Founder’s Award is given in recognition of an individual’s extraordinary contributions to the
I am writing this on behalf of all the PEM Friends in the UK, and further afield. In fact, our community extends beyond us patients to highly respected medical practitioners and many others. I want to pay tribute here to the amazing work of Carolyn Blain, founder of PEM Friends.

The aim of PEM Friends is to offer support through friendship and the group has done so much more for all of us. Her vital work has provided encouragement, support and guidance which she has extended to each and every one of us. Her dedication cannot be underestimated. Never taking no for an answer and working passionately on our behalf with the leading professionals, she always made people take notice and has put pemphigus and pemphigoid firmly on the health agenda. Carolyn has given so much of her time to support us, whether it was a PEM Friends lunch, one of the very special weekends at her home, an e-mail, a call, or so much more.

Carolyn, you be must so proud of what you have achieved. A huge thank you for the love and support you have given us. We couldn’t have got through those times without you.

Carolyn Blain founded PEM Friends and worked relentlessly to provide support, raise awareness, and organize get events for patients. Her and her husband Raymond open their home and stables to guests each year for a long weekend of fun and friends.
Solihull is a town in the West Midlands with excellent transport links and a large shopping centre containing the **John Lewis Department Store**. Once again this provided an excellent setting for the PEM Friends February lunch. The store’s restaurant, "The Place to Eat,” had one corner set aside for the PEM Friends group.

The 11 people who attended came with a wide range of issues and experiences. Some had been to many such lunches and others were newer friends. So it was good to renew old friendships and lovely to forge new ones. There was the usual genuine welcome and buzz of friends chatting and swapping stories and experiences. The good food, of course, added to the atmosphere.

**Carolyn Blain** founded PEM Friends to provide support through friendship. Tracey, who was unable to join us, says Carolyn is "the glue that holds us all together." It is also about knowing there is support and light at the end of the tunnel, as well as the sheer sense of sharing. It is often said that those who eat together, stay together. Our lunches certainly enrich our community and better equip us to face the challenges of health.

**Dr. Karen Harman**, Consultant Dermatologist at Leicester Royal Infirmary, graciously gave a considerable amount of one-to-one time where we were able to discuss our concerns and seek advice. Her gentle listening - but informative manner - made this a very precious time. We all felt privileged and special. Carolyn then presented Dr. Harman with a Marks and Spencer gift voucher, although what Dr. Harman gave to the group is priceless.

It was, indeed, a wonderful day, in which we certainly received help, advice and guidance as well as friendship and "shared an uncommon bond."
growth and future of the IPPF.

The Founder's Award recipient was Dr. Terry Wolinsky-McDonald. She has been active in the P/P community since the days of the Pemphigus and Pemphigoid Society where she was a board member, and has been a member of the IPPF Board of Directors since 2005. Dr. McDonald is a regular contributor to the IPPF Quarterly and her Psychologically Speaking column is one of the most read sections of the journal. She is also a contributor on the IPPF Email Discussion Group and frequent presenter at our Annual Meetings. The efforts of Dr. McDonald have helped the IPPF become a stronger, more patient-centric organization and establish a solid foundation for future growth.

The IPPF would like to congratulate all of our award recipients for their singularly distinctive accomplishments, and their collective efforts to better the Foundation and the lives of patients around the world.

After lunch, attendees broke up into the second group of breakout sessions of the day. Dr. Razzaque Ahmed’s presentation, Below the Belt, continues to offer information and advice to those with P/P in not so visible areas. Michelle Greer from Crescent Healthcare provided listeners with plenty of IVIg information and safe home infusions. And for those with sights on the future, Dr. Anhalt talked on New Biologics. Dr. Ahmed and Michelle have been instrumental in advocating IVIg as an effective treatment for P/P.

Returning to the main room for Plenary Session II, Treatment and Management of the Disease, Dr. Fivenson began with a Treatment Review that covered the various types of treatments currently in use and those that are on the horizon. Dr. Victoria Werth then presented on Side Effects of Common Medications. Her talk focused on the many complications that P/P patients experience while taking a myriad of drugs and how to better manage side effects when they do occur.

During Recent Successes & Strategic Directions, Dr. Sirois and Molly covered the advances the Foundation has made over the past year, and discussed where the IPPF is heading. Information on the Registry, Health Management, and Definitions Consensus gave a history and status of our current programs. Discussion on the future of the Registry and the analysis and use of the data encouraged attendees to support the research any way they can. They future of P/P is not only in the lab, but in every patient out there.

The formal program for Saturday ended with a panel discussion featuring the day’s presenters. Afterwards, attendees were invited to a Mixer sponsored by AxelaCare in Detroit’s acclaimed Amnesia Lounge. The club was all IPPF and attendees enjoyed a view of the Detroit skyline (see picture on top of pp. 4-5), delicious hors d’ourves and cocktails, and wonderful conversation and friendship building opportunities. Even though Brian Cleary was unable to attend, his colleagues (Jim Kelly, David Schaefer, and Garth Groman) made sure any and all questions were answered and everyone had a great time! Thank you AxelaCare for the wonderful evening!

After a good night’s rest, attendees joined Peer Health Coaches Marc Yale, Yvette Nachmias-Beau, Susan Gonzales-Thomas, Sharon Hickey, and Jack Sherman, to start off Sunday morning. The Patient’s and Caregiver’s Forum provided everyone a chance to not only meet the IPPF’s PHCs, but ask them questions and get answers from a patient’s perspective. Next, during The Power of One: Advocating Works!, Rebecca Strong and PHC Yvette Nachmias-Beau spoke on how they went about working with universities and how they prepared for educating medical professionals in training on P/P from a patient’s point of view.

Plenary Session III, Next Steps, was all about the future. PHC Marc Yale took the stage and spoke about the Registry and Health Management Program Updates. He encouraged attendees to not only participate, but spread the word and get everyone affected involved. Dr. Werth then provided a Clinical Trials Update and took questions from the audience. Following that, Dr. Ani Sinha officially concluded the 2011 Annual Meeting by announcing the IPPF’s 15th Annual Patient/Doctor Meeting in Boston May 18-20, 2012.

The IPPF would like to thank everyone who attended, our invited speakers, those who volunteered all over the event (Liz), and our generous sponsors.
Over the next several months, I got progressively worse. Mouth blisters continued to appear after I ate, I had constant chronic fatigue and swollen glands. My mouth erupted with white thrush-like growths in July 1995 and the first skin blister appeared in September. I had consulted many physicians and received many diagnoses and treatments for what was happening to me. None of the treatments provided any benefit or relief.

In November 1995, I was admitted to the hospital with what appeared to be second degree burns over 30%-40% of my skin surface. The tissue from my cheeks inside my mouth would completely exfoliate after each meal. I could only open my mouth about ¼ inch and had blisters inside my nose and sinus cavities. The pain was excruciating and I could barely eat or breathe. I was a walking skeleton, weighing about 100 lbs, and the blisters on my back ‘glued’ me to whatever surface they touched. I was too weak to walk and had to use a wheelchair.

A diagnosis of pemphigus vulgaris was confirmed by Immunofluorescence of a punch biopsy. My initial dose of Prednisolone IV was 180mg per day. I walked out of the hospital nine days later on a daily dose of 100mg of Prednisone, oral Novocaine, diflucan and an anti-biotic. That day marked the beginning of my journey to understand why this was happening to me.

The first thing I did was take a lesson from the clients of one of my previous employers, a social service agency. Instead of using the term “Victim of Pemphigus” or “Sufferer of Pemphigus,” I labeled myself "Living With Pemphigus."

This small change of language changed the paradigm. I was now empowered to conduct my own research. My now wife and I snuck into medical libraries in order to learn as much as we could (lay person’s are not allowed in medical libraries). During my Prednisone induced sleepless nights, I kept myself busy by reading & learning as much about Pemphigus as I could (and compulsively reorganizing our kitchen).

The second thing I did was to set a goal. I decided to be "Pemphigus Free by 2003." The significance of 2003 was that it was seven years in the future (a new-age medical belief that the cells of our bodies regenerate every seven years), and “free” rhymes with the number “3.”

The third thing I did was adopt a belief that I was not pre-destined to develop pemphigus and my immune system was not my enemy. Instead, I choose to believe that my immune system was on my side, but had become misdirected or fooled into attacking my own tissue. Instead of viewing it as the enemy needing to be suppressed, I viewed it as troubled. It needed guidance and support.

I began experiments with many modalities of medicine. Rather than list all of the paths I took and experiments I tried, most of which were dead ends, I’m going to focus on the path that lead me to where I am today, in 2011.

I was enjoying a snack with some friends and my fiancé after a yoga class --- when the blister appeared.
The first clue, to me, that specific foods may be a key to understanding, came in a TexMex restaurant a few weeks after I was released from the hospital. At that time, blisters would form in my mouth within 5 minutes of when I started to eat, and last for about 2-3 hours. That evening, the blisters formed as usual and then disappeared in about 20 minutes. I was able to repeat this phenomenon, but was not able to figure out why it happened or isolate the food that was responsible. I subsequently abandoned that as a possible clue.

Jumping forward a couple of years to 1997, I’m now living in Eugene, Oregon. Eugene is much more vegetarian friendly than Houston, and also has many more styles of medicine available. My pemphigus was fairly stable at a dose of 20-30 mg of prednisone every other day.

Among the many doctors I visited, one was an MD who specializes in chronic illness. He examined my blood under a Dark Field (Black Light) Microscope. The exam revealed, among other things, that my blood cells were agglutinating, or sticking together, much more than those of the average person. This physician’s method of treatment for this condition, massive doses of vitamins, provided no benefit to me.

Several months later, my wife and I attended a seminar that was supposed to be about the diet modality I was following at the time, raw food vegetarianism. Instead, the speaker talked about a diet based on blood type. At my wife’s insistence, I reluctantly purchased and started reading yet another book that I was sure would lead nowhere. The byline on the book was about weight control, and I already weighed a whopping 95-100 pounds (I’m 5’7”).

The book was called "Eat Right for Your Type" by Peter D'Adamo, N.D. I can still vividly remember reading and re-reading a paragraph in the book that describe how foods cause agglutination to happen. The part that fascinated me was the idea that different foods cause agglutination in people based on their blood type. In short, it is believed that foods that are harmful to me and cause agglutination can be very healthy for someone else who has a different blood type.

Now, all of my preconceptions about diet, health and disease were about to be stripped away.

In June 1997 I decided to try eating according to Dr. D'Adamo’s theory. One month later, I noticed that I was ‘feeling’ better. I had...continued from PEMPHIGUS, page 9
Continued on page 11...
slightly better muscle tone; my digestion was improving and the chronic fatigue I had lived with for the last several years would occasionally lift. The path of improvement continued and a couple of months later I reluctantly introduced meat to my diet. It seems that as a vegetarian, I was eating a very healthy diet, just not healthy for me, according to D’Amado. My blood type is O, and stereotypically speaking, people with this blood type do not thrive on a vegetarian diet.

Over the next year and a half, I continued to improve and started gradually weaning off prednisone. I took my last prednisone pill in October 1998. Although my regular physician declared pemphigus "resolved" in February 2003 (I realized my goal), I still have the antibodies in my blood. If I stray from my blood type diet too often in a short time period, I'll get an occasional blister in my mouth. It serves as a reminder to get myself back on track and eat foods that are healthy for me. The blisters normally disappear within a day or two. I have not had any skin lesions in over 12 years.

I now live a full and vibrant life. I am much healthier, in general, than I was before that first blister appeared. I am parenting my now four-year-old son who loves sports and is very physically active. I am also physically and intellectually active. I do have aches and stiffness, probably associated with both being 50+ years old, a veteran of prednisone and decades of an unhealthy lifestyle. I have avascular necrosis (dead bone tissue) in my shoulder, several benign osteoma's and high lipidemia that are all probably side effects of prednisone. They require ongoing medical monitoring, but no treatment at this time. The one thing I do not do is worry about when or if another pemphigus lesion will appear on my skin.

If I had never had pemphigus, or if I had a more popular disease that I believed would be 'cured' by modern medicine, I would never have engaged in a period of self-discovery that led to where I am today. While I wish that I could have learned these lessons in a gentler and less life threatening way, I am truly grateful for the role that pemphigus has played in my life.

Steven Shapiro is currently the Computer Services Manager for the Office of Research Services and Administration, University of Oregon. He lives in Eugene, Oregon with his wife Sharon, son Daniel, a dog, 2 cats, some chickens, and a huge garden where he can often be found planting, pruning or watching his son chase the chickens.

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**JUNE**

9 Toronto Pemphigus and Pemphigoid Support Group from 7-9 pm. (Toronto, ON, Canada) Contact kw_pemphigus@sympatico.ca

14 Ottawa Pemphigus and Pemphigoid Support Group from 7-9 pm. (Ottawa, ON, Canada) Contact victoria@pemphigus.ca

19-23 Drug Information Association (DIA) Annual Conference (Chicago, IL)

22-26 Canadian Dermatology Association 86th Annual Conference (Edmonton, AB, Canada)

25-29 10th World Congress on Inflammation (Paris, France)

**JUNE - JULY**

26-1 Camp Discovery at Camp Little Pine (Crosslake, MN)

26-1 Camp Discovery at Camp Reflection (Carnation, WA)

**JULY**

7-10 Society for Pediatric Dermatology 37th Annual Meeting (Baltimore, MD)

12-13 6th Annual Rare Disease Leadership Summit: "On the Forefront of Orphan Drug Development" (Washington, DC)

10-15 Camp Discovery at Camp Big Trout (Crosslake, MN)

**AUGUST**

3-7 AAD Summer Meeting (New York, NY)

7-12 Camp Discovery at Camp Dermadillo (Burton, TX)
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