The IPPF Annual Meeting provides a unique, quality opportunity for all who attend. While the IPPF has a website, discussion group, local support groups and quarterly newsletter, the in person face-to-face annual meetings continue to enable patients, caregivers and doctors in attendance to have cutting edge, educational and meaningful interactions. Seeing familiar faces, meeting internet friends never before seen, hugging, talking, being in the company of others with the same or similar diagnoses most people have never even heard of (and caregivers of those) is an almost unheard of and truly priceless experience.

In this age of high technology and human-machine interfacing, this very basic human experience is more psychologically important than ever before.

For those who have never attended an Annual Meeting, just seeing the photos and reading descriptions will be a positive emotional and educational experience. For those in attendance it strengthens uncommon bonds and validates and energizes. Meeting and learning from expert doctors, while sometimes overwhelming, allows the dissemination of complicated basic and cutting-edge information. It also puts faces (and bodies!) on all in attendance. Everyone is in a room full of people who actually “get it”.

Continued on page 15...

Support comes from all around us. This year, meeting attendees joined the IPPF from all over Southern California and as far as Chicago, Boston, and The Republic of Chile! Here, meeting attendees listen to entertainer/speaker Marv Rosenberg as he talks about the powers of the IPPF support network.

www.pemphigus.org
From the Top

It has been so much fun putting this newsletter together, it feels like looking through all the photos right after a wedding and remembering all the hilarious and bittersweet moments, all of the gifts and all of the challenges, the people who touch your life in ways that they will never know. Thanks you all!

We have been in a whirlwind since the Annual Meeting. A lot of amazing things happen when the forces of energy and inspiration swirl together in a room. First off, in a significant showing of trust in the direction the IPPF is heading and a pressing feeling of urgency about how much needs to be done to find real solutions for P/P folks, Mindy and Howard Unger have challenged us all with an opportunity to earn as much as $200,000 in a matching grant to double all donations received from you in 2009.

Mindy and Howard, with a deep understanding of the political, financial and scientific climate, see that the IPPF’s strategy of developing a disease registry and documenting not just the numbers of the population (although that is important to calculate costs of failure to treat) but also the course of the diseases - so that it can be evaluated what course(s) of treatments work well, in which circumstances - as our next necessary step. And, in moving toward the future, we will integrate a blood serum and tissue-sample bank which makes materials available for science researchers at the DNA, antibody and medicine-chemical levels. This is a huge step forward. One of the main barriers to better treatments for P/P is that so few people are available or accessible to help us even guess at patterns that surely exist.

One of the hardest things about this work is having to tell so many scared and hurting people who call here for some reassurance that there are not many answers. How many people have P/P? Don’t know. Is it better to start with high pred. and go down or start conservatively and add? Don’t know. How long will it take for the blisters to get under control? Don’t know. What does the scientific research show? Can’t tell, too small a sample size. Why isn’t IVIg covered by my insurance? It’s experimental for P, not enough people have been documented to decide if it is safe and effective. How much will this disease cost me per year? Can’t tell. Yes, human beings are different and have different experiences with different courses of treatments, but we don’t even have a good guess about the costs and benefits of a wide variety of things being “tried” on you, with undocumented or properly evaluated benefits or risks.

So, our goal this year is to raise $600,000. In 2008, 82% of our $330,000 budget was allocated to Patient Support, Education and Advocacy; Administration and Overhead (that’s rent, phones, etc.) cost 11% and Fundraising 7%. In 2009 we have further reduced our costs as, for example, the Internet helps us save printing and mailing costs for the paper Newsletter as more people, by reading online or printing at home, volunteer to save trees and have more of their donation go to outreach programs instead.

We have already begun the registry of individual volunteers (thanks to all of you in the Health Management Program for adding to our knowledge – the rest of you, let me know when you are ready to “be counted”!). Now we need to move into collecting medical-office data (private, not-identified) about how many immunofluorescence tests were performed, for example, and how many diagnoses made and how much insurance billing is attributable to P/P at major insurance companies, etc.

Who’s out there and what do they need? We’re working to find some answers for you, and your contribution can help tomorrow’s patients know more too.
When I was first diagnosed with PV 25 years ago, I had no one to talk with about my disease. There was no internet and I felt alone - that I was the only person in the world with PV. I was on my own looking for answers. Some of the questions I didn’t ask, and my doctor didn’t really know, were about immunosuppressive drugs. Back then, they were just beginning to use Imuran®, but my doctors didn’t know or weren’t sure how to use it, so I remained on 30mg of prednisone for 3 years. The side effects of steroids were not discussed. I had to encourage my internist to give me a bone density baseline test, check my sugar, and ask for a referral to see the ophthalmologist. So, when I started the IPPF 15 years ago, it was important that all the best information was available.

To insure the right questions are asked, the IPPF now offers patients a Health Management Program. This is a free, confidential program designed to help you understand your drugs, give information about side effects and possible preventive measures, along with needed emotional support. We provide you with a unique opportunity for one-on-one peer health coaching, not offered by most non-profit disease foundations.

Health Coaching is one aspect of HMP; another is what YOU can do to help us and others with your disease. This part of the program is comprised of questions on different facets of disease such as what drugs you are on, and in what doses. We ask whether you understand your disease, how the disease has burdened you – emotionally, physically, and financially, and when you had blood test, glucose tests, your eyes checked, or been to the dentist. When we have hundreds, even thousands of answers to these questions, we compile the data and get a good picture of disease process. Depending on where you are with your disease will depend on how often you will be asked questions. If you are on a lot of medication, you will be asked more often. If you are in remission, you might only be asked yearly. We have nearly 100 people signed on, and we thank them for giving their time for the good of the community.

I know it isn’t easy to spend time on the phone answering questions about your disease - especially if you are doing well and don’t want to think about it. But we are a rare disease. Having a patient registry provides information that is rarely gathered. Who is on CellCept® and what is the average time it takes for the steroids to be reduced, and how long does it take for a person to get off of steroids? You can ask the same questions of Imuran®, Rituxan®, and IVIG. Has having this disease interfered with or affected your social life or your family life? Has the drugs caused you fatigue? Can you access and talk with your doctor?

Imagine how important these questions are to those who have yet to be diagnosed. As rare as we are, there are thousands of us out there. The best way to get answers to these questions is if we work together. We cannot depend solely on doctors and researchers. It takes many years for double-blind drug studies to not only show results, but even begin. Patient information can be powerful. We need to depend on each other. Go to www.pemphigus.org/hmp or call us and we will send you more information. Someone will call to explain the process and set up the first session. It is more likely that answers will come sooner rather than later if we all participate.
A large hall was allocated for the session, which was open to any registrant without an additional fee, and was full for most of the session, with about 300 dermatologists in the room. The session was opened by IPPF patient liaison and Director of Patient Services & Education, Janet Segall, speaking from her personal experience as a patient, about how much a patient support organization, such as the IPPF she established, could make a difference to the lives of patients with these rare AIBD.

Dr. Jean-Claude Bystryn, from New York University, went over very clearly the clinical and pathological features needed to diagnose pemphigus and pemphigoid, and how to distinguish their subtypes and tell them from other forms of bullous diseases. His presentation included very clear photographs of the diseases and diagrams designed to make this complex area of dermatology easy to understand.

Dr. Animesh Sinha, from Michigan State University, gave an enlightening presentation about the genetic risk factors that can predispose patients to developing pemphigus, including his own research. He explained that there is an increased risk of other autoimmune diseases in patients with AIBD, the most common of which is thyroid disease, in about 20% of cases. Almost half of pemphigus vulgaris patients reported having relatives with autoimmune diseases. There are no twin studies of AIBD, so if you are a twin with pemphigus or pemphigoid, please get in touch with Janet so she can link you with Dr. Sinha, as twins with/without diseases can provide information about causes and triggers of the disease. Dr. Sinha explained in detail about the tissue types that increase the risk of developing pemphigus, particularly one called DRB1-*0402. His lab and others are actively researching genetic markers of pemphigus.

Dr. Valeria Aoki, of the University of Sao Paulo, Brazil, was nominated to speak in lieu of Dr. Luis Diaz, from the University of North Carolina at Chapel Hill, as he is on the board of the AAD, whose meeting clashed with ours. They have collaborated in very important research on what environmental triggers cause endemic pemphigus foliaceous, known as fogo selvagem, in the rainforests of Brazil. People living in these indigenous reservations, as well as people moving into the reservation, develop high antibody levels to the protein that is targeted in the skin in pemphigus foliaceous, called Desmoglein 1. There is a particular species of black fly in these reservations which is thought to be somehow related to the triggering process. Up to 1055% of healthy people in the reservations also made antibodies to Dsg1 but, crucially, not the disease-causing subtype of antibody, which is an IgG4 antibody, rather than IgG1, against a structurally crucial part of Dsg1. Dr. Aoki also spoke about an endemic form of pemphigus vulgaris that has recently been found in Brazil as well. By studying this, more information could be gleaned about factors that trigger PV.

Next, we switched gears back to the practical clinical aspects of managing the many complications of treating AIBD, which was reviewed very well by Dr. Amit Pandya, of the University of Texas, Southwestern, in Dallas. You could hear a pin drop in the audience as everyone’s eyes were glued to the screen. He spoke about the mortality of pemphigus having improved over the years, but the morbidity is what we need to improve on now. Mortality is lower due to early recognition of these diseases, earlier commencement of treatment and more appropriate use of prednisone or alternatives. Supportive treatments including sometimes overlooked basic aspects, such as nutrition, hygiene, moderate exercise to reduce muscle wasting and osteoporosis, avoiding tape; pain control, when antibiotics might be needed. He uses a very useful ‘dear doctor’ letter to the patients’ local physician, detailing all the complications that need to be watched for whilst they are on corticosteroids, including the importance of not suddenly stopping the steroids.

Extremely popular were the next two clinical talks. Dr. Russell Hall,
DOUBLE the DIFFERENCE

Do you want each dollar you invest in the IPPF to make TWICE as much impact?
Do you want to AFFIRM how important progress for P/P is to you?
Do you want to make a difference for FUTURE generations?

YOU can

- Support Systematic collection of data to identify Best Practices and Effective Treatments
- Promote fast and accurate diagnosis for early, meaningful resolution
- Ensure biologic tissue sample collection
- Enable scientific research
- Support systems for patients in crisis
- Assist with insurance challenges
- Inspire new Treatment therapies

Generous members of our community have pledged to MATCH every donation dollar we collect in 2009 up to $200,000!

Things to do today:
Donate to the IPPF
Join the HWIP
Get involved!
It was a pleasure to attend this year’s annual IPPF meeting in Los Angeles. These meetings have particular meaning to me since it was a little over twelve years ago that I suggested to Janet Segall, the founder of the IPPF, that she should think about organizing an annual patient/doctor get-together. It was my thought that those of us living in North America would benefit greatly from exchanging information with other patients and listening to leading doctors who could help us deal with these challenging diseases.

I have very fond memories of the first meeting held in Chicago. As a Director of the IPPF, I am very pleased and proud of how far the organization has come in 12 years.

The Patient/Doctor Meeting was a wonderful event. The weekend’s events were kicked off on Friday night with a newcomer reception and orientation. For those individuals who were recently diagnosed, the first few months are a particularly unsettling time. I am sure that many of the patients and their families benefitted from the opportunity to chat informally with IPPF board members and other patients who have had the disease for some time. There were folks there from all over the United States and from as far away as Chile and Canada (me). I think everyone benefitted from an opportunity to exchange information in a relaxed and pleasant environment.

The Saturday session was well attended with over 100 patients, spouses and care-givers. Dr. Grant Anhalt, one of the world’s leading authorities on Pemphigus and Pemphigoid, who spoke at the original Annual Meeting in Chicago, (and I believe all of the meetings since then,) began the day with an excellent Introduction to Pemphigus. It was gratifying to see the evolution in knowledge and treatments. He was followed by a number of other leading doctors (Grando, Haley, Woodley, and Sinha to name a few) and health care specialists who spoke effectively on the various trials under way and the results being achieved with IVIG and Rituximab, two treatments that were not around when I was first diagnosed with pemphigus. While prednisone, Imuran® and CellCept® are still the first line treatments, there are now a range of new options that are being used and evaluated to treat these diseases.

The afternoon session contained an array of interesting speakers that discussed everything from the business of medicine, a rather sobering but necessary presentation to Disease with Laughter, and Oral Medicine. The day was filled with excellent presentations that addressed pemphigus and pemphigoid from a variety of perspectives. I am sure that all of the attendees benefitted greatly from receiving these detailed briefings.

The day concluded with two very important undertakings, a silent auction and a raffle. The silent auction was remarkable. Sitting on a rectangular table, about 50 feet long by 20 feet wide, were a large number of gifts donated by various companies in the Los Angeles area. These items ranged from dinners at some of the city's best restaurants to a day at a spa. During the course of the day, meeting attendees bid on these items. The IPPF raised a significant amount of money from the generosity of those individuals who purchased raffle tickets and donated items.

Another feature that made this event unique was the four booths at the back of the room. In each booth there were representatives from organizations who were there to discuss wound care and patient support. It was great to have AxelaCare, Centric Health Resources, Crescent Healthcare and National Rehab in attendance. Thank you for coming and for supporting the IPPF. It was greatly appreciated by all.

The day concluded with a gala dinner. In addition to the great food and company, there was a moment that made this day very special. Marv Rosenberg, who spoke earlier in the day on maintaining a positive attitude, led the group in singing the famous disco song, YMCA, but with words that tell the Pemphigus and Prednisone story (see the lyrics on page 11). This was truly memorable and touching. A great deal of thanks goes to Marv for this original and very heart-warming entertainment. A great time was had by all.

The meeting wrapped up on Sunday morning with a Patient Support meeting. Thank you most go to Molly, Janet and Will who helped organize this amazing event. I know it was of great value to everyone who came. I look forward to seeing the taped highlights of this memorable couple of days as soon as they are available.
I am from Chile, I have Pemphigus Vulgaris and I traveled from home to attend the 2009 annual patient/doctor meeting that the IPPF organized and hosted. It was certainly an important experience for me; I learned about my disease by being able to know people who also have it, sharing with them and by having the chance to hear and meet doctors that are dedicated to study this rare thing.

I was diagnosed with Pemphigus Vulgaris in 2007. I was lucky to have been diagnosed less than 3 months after I noticed the first lesion on my mouth and to start treatment immediately. I found about IPPF surfing on the internet at the beginning of my illness but I always saw it as an organization far from me that I could use to get some general information.

Last year I found out about a serious problem that I developed on both my hips due to the use of prednisone. Knowing it made me realize that I needed to have a more active role in the control of my disease and I started looking and searching again on the internet; that's how I decided to get in touch with the IPPF and ask them for some orientation. That's how my wife and I found out about the Patient/Doctor Meeting in LA and we decided to go.

The private health system in Chile is very good and much, much better than the public one. But there are not many people who have access to it. The fact that there is very little data from the public health system (which is the one that concentrates on most of the population), in addition on how weird (translation “rare”, Eds.) pemphigus is -- so there are insignificant number of patients to assure that physicians achieve enough experience to deal with it and manage it's treatment in a proper way.

Until I attended the annual meeting, I had never met in my life anyone who had the same disease, neither had I had the chance to speak with physicians who were dedicated to this area with the level of expertise and experience of those who participated there. Attending the annual meeting allowed me to know about the different treatments for the disease that are being used in the US and about how different people who have lived with the same disease handle it.

As a concrete result of my attendance, I would point out that I did get new ideas about my treatment to talk about with my doctor, that I realized that I needed to clarify criteria with him, that my wife and I confirmed the need of being more “in” the treatment as active agents of it, and that it was really good for us to get close to IPPF and know that we can count on them and their support from the US to handle my disease.

Filipe
Below: The IPPF recognized its Annual Award winners during its Gala Dinner Celebration. From left to right:

Founder’s Award: Dr. David Sirois; Doctor of the Year: Dr. Ani Sinha; Lifetime Achievement: Mr. Alan Papert;
Star Award (Education): Dr. Terry McDonald; Star Award (Outreach): Mrs. Cathy Burns;
Star Award (Patient Support): Mr. Marc Yale

Also pictured is IPPF Director of Communications Will Zrnchik who was presented with two Gold Awards from
the Marketing and Communications Professionals Association for the IPPF website and e-newsletter.
Right now, as many of you know, once you’ve been approved for disability most cases take 24 months before you can be approved for Medicare. In last Winter’s issue, we talked about a Congressional bill that would eliminate the 24 month waiting period for Medicare once someone has been approved for disability (SSDI).

Well, the Medicare Rights Center let us know that the bills have been reintroduced as bill – HR1708, S700, Eliminate 24 Month Waiting Period for People with Disabilities. Whether you agree with a one payer system, Universal Healthcare or not, no one diagnosed with pemphigus and pemphigoid who has been approved for disability should have to agonize over how they might pay for the treatment they need. The worst time for our diseases is usually the first 24 months. We encourage everyone to please contact your Congressional representatives and ask them to co-sponsor or support this bill. This is a bipartisan bill and representatives from both parties are supporting it. Getting treated at an emergency room that is overcrowded by doctors who have no idea what pemphigus or pemphigoid is while waiting 8 or more hours just to see someone -- other than emergency room residents -- is not acceptable.

Let’s get together and make sure new patients suffering from pemphigus and pemphigoid get the help they deserve!
Public Affairs. Under the leadership of Bill Green (Chair of the Committee on Public Affairs) and Lauren Gross (AAI Director of Public Policy and Government Affairs) the Public Affairs committee decided to reach out to patient groups to allow them to meet immunologists and future scientists interested in each of our own research areas – for example, I spoke with many focused on B-cell issues which is a culprit in P/P. We also pledged to help the AAI include real and passionate stories in congressional advocacy, as meeting patients is what moves action! Advocacy and educational efforts by AAI that target Congress and disease-specific interest groups can influence funding priorities.

We are in an incredible era in immunology when the scientific advances in labs are now being translated into new approaches in disease prevention (i.e., the HPV vaccine), diagnosis (i.e., subsetting of lymphomas and leukemias using monoclonal antibodies) and in therapies (i.e., the success of monoclonal antibodies and fusion proteins to interrupt key components of the immune response). We thank the AAI for the opportunity to spread the word about P/P research opportunities, for their help in connecting us with advisors for our disease registry and for their generous spirit in reaching out to the patient community.

It is a time for all of us to celebrate these achievements and the success of immunology in advancing medicine and in advancing fundamental science. It is a time to encourage further support of research to capitalize on new technologies and the advances that have already been made. Working together the IPPF, other patient groups and the AAI, plan to do just that!

IPPF Inspires Famed Musician

The 1960s were a young beach boy’s dream come true as his song rocketed to #6 on the Billboard Top 100. Marv Rosenberg, who authored the debut single "Image of a Girl" for The Safaris, has a special place in his heart for P/P patients.

To show his support for the IPPF, Marv sang a song at the 2009 Annual Meeting’s Gala Dinner Celebration. His words had guests clapping and singing along as they knew the IPPF and its Community are there when they need information, advice, and support.

Contact YOUR Representatives TODAY!

Visit www.house.gov and www.senate.gov to contact your representatives.

and let YOUR VOICE be heard

Lyrics by Marv Rosenberg (2009)
Original Y.M.C.A. Lyrics by Henri Belolo, Jacques Morali, Victor Willis

REFRAIN
IPPF, oh yes we are the IPPF
The future looks bright,
As researchers fight,
(To find a) cure that's near in sight.

And all you... who are here tonight.
We thank you... you're a beautiful sight.
What we hope... and it is sincere,
That our meeting we see you next year.

REFRAIN
IPPF, oh yes we are the IPPF
The future looks bright,
As researchers fight,
(To find a) cure that's near in sight.

to contact your representatives.
First Patient/Doctor Meeting in Italy Concludes

Anna Lisa Zorzi Riccardi

The first Patient/Doctor Meeting was held in Italy on May 18, 2009 in the IDI Dermatological Hospital, Rome.

The meeting was extremely interesting and the room was filled with patients coming from all over Italy. Topics included: discussions on what pemphigus is, oral pemphigus, how to control the disease, the side effects of prednisone, other treatments, and the bureaucratic and legal steps a person has to follow to obtain social security support. After a light lunch, there was a question and answer session.

Thanks go to the dedication of Dr. G. Cianchini and of two pemphigus patients, Sara and Giovanna, who succeeded through hard work, in getting together so many people.

Most of the participants already knew a lot about their disease but the doctors’ presentations were clear, simple and to the point. This was the very first time in which patients from the North, South and Central Italy could get to know each other, share their experiences, hear doctors speak about pemphigus and answer their questions.

No doubt it was a great success. No time was wasted. Sara and Giovanna had prepared a draft for a future Italian Pemphigus Foundation, which was read and approved by those present. In the next days we shall follow-up on what has to be done. Dr. Cianchini gracefully accepted to be a member of the Board.

Our great wish is also to be part of the IPPF and I believe my role will be to between the IPPF and the new Italian Pemphigus Association.
Join Raymond and Carolyn for Another Exciting PEM Friends' Away Weekend

Excluding the hosts, Raymond and Carolyn Blain, we already have the names of eight people who will be attending, so hurry towards a decision about joining us! These weekends are great fun, and of particular value to those experiencing a ‘bad time’ with their pemphigus or pemphigoid, as well as some in remission who will also be able to empathize with you. At these occasions, remember you’ll be amongst friends who really do understand what you’re going through. I don’t think anyone has ever stayed for one of these weekends and not gone home feeling they’ve really benefited from the companionship, the fun we’ve all had and the very relaxing venue, which is in the countryside.

Please note that ‘carers’ are particularly welcome, as they also find these weekends to be of great value and benefit.

Quite a number of friendships have developed too – another great benefit to come out of such events.

There are accommodations available at the main venue, The Stables (www.shortletsmanchester.co.uk) and for those who’d prefer to be in a hotel, there’s the three star Best Western Smokies Park Hotel just a mile away.

If you’re interested in spending the weekend with us or just attending the Gala Dinner on Saturday evening, held in Raymond & Carolyn’s home, please do get in touch, and I’ll send further information.

Tel: 0161 343 7100/07831 349978 or stayinmanchester@hotmail.com.

PEM Friends Meeting Recap

For the first time since our group started meeting two or three times a year for lunch, on the 20 February 2009 we held a lunch outside London. We met in the restaurant of John Lewis in Solihull – not far from Birmingham (which is roughly in the centre of England).

The venue was excellent and the restaurant staff couldn’t have done more to make us welcome. We had the biggest turn-out yet for a lunch which, including the three doctors, totalled 26 PEM Friends. We met from 11 am til the last group of eight people left at 4.15 pm!

Our specially invited guest for the lunch was the Dermatologist, Dr. Karen E. Harman FRCP, DM, MB, BChir., who practices within the National Health Service at Leicester Royal Infirmary, as well as having a private practice at the Spire Hospital, Leicester.

Just the day before the lunch, we were contacted by Saaeha Rauz PhD, FRCOphth (Miss). Senior Lecturer/Consultant Ophthalmologist at the University of Birmingham, who asked if she could come along for a short time, to establish contact with us, and to bring with her a colleague, Geraint Williams. He is currently initiating a long term prospective study of ocular and oral mucus membrane pemphigoid, having received a sizeable grant.

Miss Rauz is keen to initiate some form of dialogue between patients and professionals involved with pemphigus and pemphigoid - so hopefully we can soon begin to take this forward and possibly involve both Dr. Harman and Dr. Setterfield (who practices in London). It was fortunate that Dr. Harman, Miss Rauz and Geraint were able to take advantage of the occasion of our lunch to get to know each other a little before Miss Rauz and Geraint had to leave.

After a hasty lunch, Dr. Harman then moved between small groups and answered questions and talked at length on whatever aspect anyone wanted to learn more about. She was so incredibly selfless and generous with her time and knowledge and everyone was immensely grateful to her.

Dr. Harman must have talked non-stop to everyone for at least two hours or so. What a special person she is.

The next lunch will be in October 2009, and we may have to bow to pressure from those in the south-east, and have the event in London. If we do, the following one in February 2010 will definitely be in Solihull again! xo xo Carolyn
The next two presentations were about the work of the International Pemphigus Definitions group, in order to develop a consensus about how pemphigus is staged clinically and how it should be graded.

**Prof. Dedee Murrell**, Chair of Dermatology at the University of New South Wales, St George Hospital, in Sydney, Australia, explained how she and Vicky Werth had coordinated meetings between disparate groups of dermatologists from all parts of the world who are experts in pemphigus, to hold face-to-face meetings alongside international congresses, to debate the very important topic of defining disease stages in pemphigus – in other words, what constitutes when the disease is under control, a remission on/off therapy, what minimal therapy for pemphigus is, what is a flare, what treatments and doses should be part of clinical trials before the patient is said to be ‘resistant’ to treatment.

As a prelude to this, she and her fellow, Linda Martin, had reviewed all studies of pemphigus published with more than 5 patients and had found that more different definitions of outcome measures were used (116) than there were studies (96). In order to compare treatments in an orphan disease, a statistical method, called meta-analysis, is used, which can be a very powerful tool for rare diseases for which very large randomized trials are impossible. However, to do meta-analysis, you need uniform outcome measures to be used in each study. Since the Definitions consensus for pemphigus was published in the JAAD last year, new trials are including these.

**Dr. Victoria Werth**, Professor of Dermatology at the University of Pennsylvania, gave the second presentation on the advances being made in developing grading systems for pemphigus and other AIBD. She explained that there were certain standard steps that needed to be completed in order to develop and validate proposed...
Continued from AAD, page 14...

disease extent and activity measures. She has successfully done this before for another autoimmune skin disease, lupus.

There are two proposed disease extent and activity measures, one developed by IPPF MAB member Prof. Michael Hertl, in Germany, called the ABSIS, and one developed by the Pemphigus Definitions group, including the experts from around the world, as well as Prof. Hertl, and other German dermatologists, as a group, called the PDAI and PSS. Dr. Werth reviewed the results of a validation study done on patients with pemphigus at Penn, with several expert dermatologists, mainly from the IPPF group, performing these gradings on the same patients on the same day. This is coming out in the Journal of Investigative Dermatology soon. While both the ABSIS and PDAI were sensitive, the PDAI was more sensitive at lower degrees of involvement and had a higher intra-rater reliability coefficient. She spoke about another study using photographs of these same patients, and other more severely involved patients, being assessed similarly but via a secure IPPF weblink, so that international experts could participate as well.

Finally, the session closed with a unique presentation by IPPF President, Dr. David Sirois, Professor of Dentistry and Oral Medicine at New York University. He spoke about the opportunities for the pharmaceutical industry to support patients with orphan diseases, including AIBD, by using the fast tracking of applications for approval by the FDA, using the Orphan Drugs Act, 1983. Of 1700 new drug applications, over 300 have been approved, or about 11 new drugs for orphan diseases per year.

While orphan diseases may be rare, because patients usually require these expensive new treatments for many years, it is worth pursuing by these pharmaceutical companies as if they are given an approved listing for that indication, insurance companies are then obliged to fund them, and those drugs which have been approved for orphan diseases have averaged an expenditure of $500M/year. Thus, the changing pharmaceutical marketplace for ultraorphan illnesses present a unique challenge and opportunity for partnerships between Patient Advocacy Groups like the IPPF, insurance companies, and specialty pharmacies to develop novel and favorable models for expanding the orphan drug research pipeline and accelerating clinical trials that can lead to improved therapy and treatment outcomes. On the other hand, insurance companies, he said, were not going to spend time looking into projected costs for rare orphan diseases.

Judging by the high attendance, applause and questions, there was much enthusiasm for the session. At the AAD, the audience is asked to grade each presenter and only sessions with good gradings are invited back the next year. We anticipate excellent ratings based on the attendance and hope to return with this session at the AAD next year with more new information for the dermatologists across the globe.

Continued from SUPPORT OF PEOPLE, page 1...

I attended my first Annual Doctor-Patient Conference in NYC in 2002. It was gratifying both socially and psychologically. Instead of being a person with a rare illness no one had ever heard of, I was surrounded by others in the same position. We didn't even need words to communicate. That meeting was relatively tame by this year's standards, but the benefits were immeasurable. After attending numerous meetings, I can honestly say they are always worthwhile and never boring. In fact, the meetings seem to get better every year, although no one imagines how they can continue to improve!

Many people with chronic illnesses and other problems feel lonely, isolated, misunderstood and invisible. The IPPF Annual Meetings don't allow time for loneliness, isolation, misunderstandings or invisibility. In fact, the meetings are so jam packed with invaluable information and social/educational activities that the biggest complaint is sheer exhaustion (mixed with a sense of exhilaration). Although it is extremely challenging to travel in these difficult economic times, I would encourage those of you who have never attended an Annual Meeting to find a way to attend at least one. The IPPF Community is not large, but is ever growing. These meetings consistently educate and validate patients and caregivers (family, friends), and offer the necessary social support which will always be so important for human beings' mental feelings of well being and connectedness. The success of this last meeting, worked on by so many for so long, will be remembered and cherished by all.

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.
The IPPF received official notification that it has been awarded two prestigious Hermes Awards (www.hermesawards.com)! The IPPF Community Website (community.pemphigus.org) received a **Platinum Award** for Design/Web Site Overall, and the IPPF Informational Website (www.pemphigus.org) received a **Gold Award** in the Web Site Overall category! The IPPF also received **Honorable Mentions** for our eQuarterly and the monthly IPPF eBlast.

**IPPF Continues on Award-Winning Path**

**Hermes Creative Awards** is an international competition for creative professionals involved in the concept, writing and design of traditional materials and programs, and emerging technologies. Entries come from corporate marketing and communication departments, advertising agencies, PR firms, design shops, production companies, web based innovators and freelancers.