**Amanda and Her Support Network: Three Years Later and Still Going Strong**

Much has happened since our daughter, Amanda Staso, was featured in the Winter 2006 issue of the Quarterly. At that time, she was in eighth grade, and had just started treatment with Dr. Grant Anhalt after receiving a diagnosis of pemphigus vulgaris (PV) on her 14th birthday in February, 2006.

By the Summer of 2006, Amanda had almost tapered off the prednisone, but was still taking 2000 mg of CellCept® a day. She was feeling pretty good, and was nervous, but excited to start high school. Then, in early August, she got sick. It took several doctors to figure out what was wrong, and it turned out that she had contracted the coxsackie virus.

Things were confusing because this virus causes mouth sores, just like the PV. The virus resolved, but the mouth sores did not. The virus triggered a full blown flare.

Amanda was very sick. She missed her first two weeks of high school, and had to go back on high doses of prednison and begin the long taper process all over again. What should have been a fun, exciting time in her life was consumed with physical and emotional turmoil. Physically, her face was swollen, she gained weight, suffered from migraine headaches. Emotionally, the side effects were just as bad. A very

*Continued on page 11...*

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**The Staso Family at Home. Pictured are (l-r) Keith (father), Amanda, Wendy (mother), and Jonathan.**

[www.pemphigus.org](http://www.pemphigus.org)
From the Top

This issue of the Quarterly focuses on our theme of Support. Support is one of the founding principles of the IPPF, stated in our Mission as: “The IPPF provides direct access to innovative and effective support that:

• promotes the very best health care,
• improves quality of life,
• stimulates community resources,
• advocates for favorable government policies,
• accelerates the pace of scientific discovery, and
• is the world’s best source of information on P/P”

Interestingly, this issue of our Newsletter became one of our most jam packed when we announced the theme. What I loved, as all the stories came in, was the many different ways people have found to provide support to each other through the IPPF.

Marc answers specific questions and cheers people on in the Forum; Mindy offers to use her expertise to promote donor development (Bio page 4); Amanda submits an English paper for a Senior project, on rare disease funding challenges, and takes the message to her high school (www.pemphigus.org/amanda); our insurance coverage advocate, Brian, secured IVIg and/or Rituxan for two extra-challenging insurance coverage puzzles for IPPF members (see page 4), Alan and Terry made presentations at dental professional Seminars/Conferences to educate about P/P (pp. 5 and 6); Madeline and Danielle created new Wound Care information sheets (www.pemphigus.org/materials); Cathy has gathered more than $5,000 worth of items for auction at the Annual Meeting (www.pemphigus.org/AM2009); Rebecca finished the video – check it out at www.pemphigus.org/youtube (there’s both an educational one and the tear jerker); Badri and Miki edited endless dry medical documents and fun new brochures; Will developed a News and Info page on the website (www.pemphigus.org/news); and Janet has undertaken a rigorous Professional Health Coach Certification Program which will result in her accreditation by the American College of Sports Medicine, and will allow her to expand her coaching services to even more patients in need (www.pemphigus.org/hcmp). Many support us with direct donations.

When I was a Trauma Chaplain we had a few standard “prayers” that could be of service no matter the spiritual (or not) background of the person being ministered to. My favorite ended with, “When the cold dark wind blows through the hollows of your soul, gather together and share what you know to be true.”

It’s a scary, rainy night here in Sacramento as I write this; the economy is troubling and someone today was told they have pemphigus. All we have to comfort us on this crazy journey is the compassion shared by another. The magic thread, the “uncommon bond,” that draws each of you into the service of other P/P patients is the deep understanding that comes because you also have walked that path, and can share what you know to be true.

I look forward to the gathering together part, at the IPPF Annual Meeting, April 24-26, 2009.
One of our volunteers soliciting gifts for our Annual Meeting auction mentioned to me that several of the places she has contacted asked the question, “Does this disease affect kids?” When they asked her that question, she thought, “Yes, of course it affects kids.” She remembered how difficult it was on her daughter and her whole family when she was diagnosed. I immediately understood what she was talking about.

Just because a child doesn’t have a disease, doesn’t mean that the “kids” are not affected. As we all know, people and companies are more inclined to give to organizations that involve diseases that affect kids. Also, getting any kind of media acknowledgement without cute kids is very difficult as well. And, although we do, unfortunately, know children and young adults who are diagnosed each year with one of our diseases, most of our patient base is people over 40.

We often overlook the effect that a disease like pemphigus or pemphigoid can have on a family. It is so important that not only should the person with our diseases get the support and care that they need, but that kids, spouses, significant others, grandparents, and close extended families have the opportunity to find sympathetic ears and hearts for their needs as well. Sometimes, diseases can be more devastating to the families than the patient themselves.

When I was diagnosed some 25 years ago, I was raising my 6 year old daughter alone. Although I had the support of family, my daughter was emotionally devastated. She had lost her father when she was too young to remember him, but nevertheless, he had made his imprint on her life. She started exhibiting out of character behavior which was very concerning, so I brought her to a child therapist. After 3 months of therapy, she revealed to the therapist that she was afraid that she would be an orphan, and who would love and take care of her? I told my dermatologist at the time, Dr. Clarke, what had transpired and she said, “Bring her in. I’ll talk to her.” So I brought my daughter to see Dr. Clarke. Dr. Clarke went to her desk and took out her business card. She said to my daughter, “You’re mother is not going to die. I want you to take this card. It has my name and my phone number on it. If you have any questions about anything, you just call me.” When we got home, she put the card in her clothes draw where it sat for many years. Her uncharacteristic behavior stopped. She never used the card, but just knowing that the card was there made all the difference in the world.

Our diseases affect everyone in our families and if anyone ever asks whether your disease affects children, the answer is always “Yes!” Emotional issues can sometimes be more difficult than physical ones. At our Annual Meetings, we always have a Caregivers meeting during our Sunday event. We have a section on the website for Caregivers. From my observations, women seem to be more open to therapy than men, but there is nothing shameful in seeking help. Communication is so important in keeping families together.
New IPPF BOD Member Brings Vast Experience to the Mix

The IPPF is pleased to welcome the newest member to our Board of Directors. Mindy Unger is a mother of three children, ages 19, 16, and 9 and is actively engaged in a number of philanthropic activities.

Mindy graduated from Binghamton University in 1982 with a B.S. in Accounting and received her CPA. She was an Auditor with Deloitte Haskins and Sells (now Deloitte and Touche), a Vice President at First Chicago and the Director of Accounting at Clarendon Ltd.

As a Board Member of Bet Torah, where she is currently Chair of the Ways and Means Committee, Mindy is responsible for more than doubling the fundraising efforts of previous years. She is a founding and active member of the Neshamot Fund, a Westchester Women’s Impact Philanthropy Group. She is also actively involved in various volunteer positions, from monthly visits to the Pleasantville Cottage School, a residential treatment center caring for 200 emotionally troubled youngsters, to being treasurer for multiple school plays.

Mindy is excited about using her financial, organizational, and fundraising skills to benefit the IPPF. Having the disease herself, she is most anxious for the IPPF to continue developing educational programs and research efforts.

Advances in Pemphigus Research

The IPPF has always been instrumental in supporting clinical and scientific meetings. In addition to supporting the American Academy of Dermatology’s (AAD) Symposium on Autoimmune Blistering Diseases, the IPPF is co-sponsoring the International Pemphigus Meeting in Bern, Switzerland in June 2009. This meeting will gather the finest minds in the world studying and researching pemphigus.

Subjects include: models in pemphigus, cell signaling, immune responses, unconventional therapies, and how stem cells might play a part. Janet Segall, IPPF Director of Patient Services & Education, will add a human face to the ramifications of these diseases among the scheduled scientific discussions.

The hope for better results comes from the work of people speaking and attending this meeting. The IPPF is proud to partner and co-sponsor such an important discussion and thank all those involved. The registration deadline is March 31, 2009. Anyone interested in attending this meeting should register at http://www.kas.unibe.ch/pemph09/.

In a number of P/P patients, standard treatment plans just don’t seem to work so other evidence-based treatments may be prescribed. IVlg or Rituximab – two expensive treatments – require approval by a patient’s medical plan. Many insurers choose to deny these treatments.

The IPPF and AxelaCare, a national specialty infusion pharmacy, have developed a Patient Advocacy Program to be launched at our Annual Meeting as a special ACTION! Event. AxelaCare’s Insurance Advocates will work with P/P patients and their doctors to get these treatments approved by specific insurance providers. If you have been denied, AxelaCare guides you and your physician through the appeal process using a successful system developed with P/P patients in mind.

This system was tested with two IPPF members seeking IVlg and/or Rituxan® who struggled to get these services after a lack of success with “lesser” treatments. Our partnership was started to help P/P patients understand their health insurance benefits and receive coverage for evidence-based treatments while navigating the insurance maze. AxelaCare knows complex reimbursement issues and high out-of-pocket costs prevent patients from starting and maintaining their therapies.

So, if you would like to encourage coverage from your insurance provider, bring your policy, any denial letters, and any documentation from your doctor suggesting further treatments, to get a FREE consultation, sample letters, supporting articles from one of the IPPF/AxelaCare Advocates! Email Molly at molly@pemphigus.org. Also, you can email Rebecca at rebecca@pemphigus.org to discuss her successful experience with the process.
Raising Awareness in Boston: Yankee Dental Congress

Each year, the Massachusetts Dental Society, in cooperation with the dental societies of Connecticut, Maine, New Hampshire, Rhode Island, and Vermont, hosts the Yankee Dental Congress (YDC).

The exhibit floor showcased innovative products, technology and services, as well as the finest educational courses in dentistry. Courses are offered not only to dentists, but to students, hygienists, technicians and other office staff.

For the third time, the IPPF Boston Support Group (BSG) provided an educational table at YDC using a modified version of last year's pop-up display provided by the generosity of Burt Gordon.

The group knew from previous years that many people walked by scanning the name at the top of the booth and stopped only when they recognized the name or message. This lead to the thought that what was being sold at the table was knowledge -- or rather awareness of pemphigus and pemphigoid -- with the IPPF being the source of knowledge. The BSG hoisted a banner with the words “Boston Area Support Group Raising Awareness” without specifying awareness of what. The idea, put forward by Burt, was to arouse curiosity, draw visitors over and give a chance for the Support Group to discuss pemphigus and pemphigoid and to distribute hand-outs to those interested. The IPPF sent brochures for dental offices and newsletters to help spread the word.

Alan Papert asked Legal Sea Foods, a restaurant near the convention center, to hold a fundraiser in support of the table. Unfortunately, due to the tough economy, they had no budget for sponsorships this year. Instead, Legal Sea Foods gave a $59 gift certificate to raffle. Business cards were collected and the lucky winner was Jessica McMullin of Hartford, Connecticut. A donation collection box was placed close to the card collection box. Few people shared their business cards so we will brainstorm about how to engage visitors better.

The BSG members did find a contact with the Boston University Goldman School of Dentistry where they can volunteer in the classrooms to show dentists-in-training real examples for diagnosing the diseases. Educating and informing front line dental health professionals improves diagnoses times.

Because of the current financial crisis, dentists are not shopping for new equipment so the exhibition had more empty spaces in the hall and less pedestrian traffic. Unfortunately, this resulted in fewer visitors to the table than was expected, but we learned a lot and made more people aware.

The YDC is the fifth largest dental conference in the US and the largest in New England.

The 2009 convention was held January 29-31, 2009, at Boston’s Convention Center bringing together over 28,000 dental professionals.

2009 marked the third year the BSG attended the YDC educating the dental community on pemphigus/pemphigoid.

Special thanks goes out to the volunteers who donated their time to staff the BSG table: Carol Fischman, Alan and Gloria Papert, Dr. Laurie and Sylvia Tolman, and Hayat Weiss.

If you are interested in raising awareness in your community, contact Molly Stuart, IPPF CEO, at molly@pemphigus.org.

What is this?

Read Dr. McDonald’s article, Talking With Others About Your Diagnosis, on the next page to find out!

What are Antibodies?

Antibodies are produced by cells of the immune system that live in bone marrow. The antibodies circulate in the blood, reach the skin, and bind to a specific protein. This protein’s normal function is to keep the cells bound together. When the antibodies bind to the protein, the cells fall apart and blistering of the skin and mucous membranes occurs.
Painful and scary symptoms no one seems to be able to explain or understand; a diagnosis you have never heard of before; understanding the actual illness; treatment options – most of which have not been FDA approved or may be considered “experimental”; side effects to consider; possible remission but no cure... Just trying to take in all of the above is totally overwhelming. Now, how do you explain it to others?

Before you’ve even adjusted you will be asked by others how you are or what you “have.” How do you answer these questions? You will try to find a relatively easy to understand explanation (e.g. “My body’s immune system is not working correctly; it is attacking my body.”)

I find that some people are even confused on the difference between “autoimmune disease” (AID) and “acquired immune deficiency” (as in AIDS). [See Terry’s full article about AID vs. AIDS on our website at www.pemphigus.org/aid or call 916.922.1298] It is disturbing when others are scared that they will contract pemphigus or pemphigoid from us.

While there has been education about MS, Lupus, Arthritis and other autoimmune disorders, the more rare ones remain a mystery – and a scary one at that. From a psychological point of view all of this puts people with these rare autoimmune diseases at a distinct disadvantage. Now you need to cope with the fears of others as well as your own. Like most fears, they can often be addressed with a good dose of information.

Personally, I find it easiest to just say pemphigus is an autoimmune disease like Arthritis or Lupus. Since I have arthritic hands I can just put out my hand and say it is not a disease I can give anyone any more than I can actually give someone Arthritis. If people want more information, I usually just refer them to the website. Those who go learn a lot very quickly. Education is part of the mission statement of the IPPF. From the website you can get and give out key points to raise awareness and minimize fear in others.

If, as a patient, you feel compelled to further explain your particular autoimmune disease, a few copied/printed pages may suffice, or you can write a succinct explanation on index cards which can easily be carried around in a wallet (or use the sample at the left).

By the time this article is in print, I will have presented at the University of Pittsburgh Dental School for dentists receiving continuing education credits. I am not an expert on dentistry, but I understand the challenges of this disease and I have help and support from Janet and my fellow Board Members including Dr. David Sirois. I have made this opportunity happen through sheer persistence. I feel very strongly about patients getting their diagnoses in a more timely fashion.

I truly believe we are all capable of making a difference for others by giving our time and energy to help people -- both doctors and our community -- become more aware of diagnoses and challenges. Whether it is time, money, or other resources, every little bit helps! My hope and belief is that we can all touch others in positive ways and that whatever we are able to contribute of ourselves will make a difference.

What is Pemphigus?
Pemphigus is a group of rare blistering disorders of the skin. The immune system produces antibodies which erroneously perceive the skin and/or mucous membrane tissues as foreign and attack them producing burn-like lesions that will not heal. There is no cure and if left untreated, could result in death. They can be controlled with a variety of drugs and treatments.

Here is a helpful cutout to carry with you when explaining antibodies and pemphigus to others.
Advocacy of the IPPF Through the National Health Council

Molly Stuart, J.D.
CEO, IPPF
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A member of our Board of Directors and I attended the National Health Council’s (NHC) annual meeting February 11-13, 2009. The National Health Council sets operating Standards of Excellence for its members – such as the IPPF and over 50 of the nation’s leading patient advocacy groups – regarding budgets, policies for working with pharma companies and expenditures. The NHC advocates in Washington, D.C. and is the only organization of its kind that brings together all segments of the health care community to provide a united voice for more than 100 million people with chronic diseases and disabilities and their family caregivers.

Made up of approximately 110 national health-related organizations, NHC’s core membership includes the nation’s leading patient advocacy groups. Other members include professional and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device and biotechnology companies.

The main thrust of this conference is the unique crisis and opportunity presented by our economic situation and the impact of the healthcare system. The NHC, as our advocacy arm in Washington, has developed the Campaign to Put Patients First. The Campaign to Put Patients First is a nationwide initiative dedicated to mobilizing people with long-term diseases and disabilities to achieve effective and affordable health care – health care that meets their personal needs and goals. The NHC reported that the US spends TWICE as much as any other nation on healthcare and comes in 18-20th on quality measures.

Over the next three years, the National Health Council plans to recruit one million people with long-term diseases and disabilities to make their voices heard. The five health care principles that the NHC will advocate to healthcare policy makers in Putting Patients First are to:

• Get health care coverage for everyone
• Curb costs responsibly
• Make sure everyone has coverage even if they have pre-existing conditions
• Get rid of lifetime caps that limit the total amount of benefits provided by health insurance
• Respect people at the end of life

These five health care principles for Putting Patients First will guide efforts to improve health care in this country. Many are joining the Campaign to make sure that the collective voice of people with long-term diseases and disabilities is heard.

How Individual Patients and Citizens can Help

SHARE YOUR STORY: As someone affected by a chronic disease or disability, you have a compelling personal story to tell. Why not tell it? Both policy makers and the media respond favorably to personal stories.

By sharing your experiences in dealing with the health care system, you can persuade elected officials to ensure effective and affordable health care for all. We hope to record some videos at the IPPF Annual Meeting, or you can send the NHC a brief written story (preferably with a photo of yourself) or upload a video clip at www.puttingpatientsfirst.net/sharestory. As much as possible, please focus your story on our Five Health Care Principles (http://nationalhealthcouncil.org/forms/5-healthcare-principals.pdf) and the personal challenges you have faced.

As Rebecca Oling did in offering to tell her story on the Richard Cohen Show last fall (www.pemphigus.org/richardcohenshow), individual passionate stories can set the tone for change in a system that fails many of us. Stories can advocate for change and create awareness of those diseases that often fall through the cracks of our profit-driven healthcare system.

Please let the IPPF know if you are willing to be called upon for media opportunities for taping at our Annual Meeting, or for chances to tell your healthcare story before Congress.

EMAIL: info@pemphigus.org with the Subject line: Healthcare Advocate
PHONE: Call 916.922.1298.

You may also sign a petition online at the NHC website, www.puttingpatientsfirst.net/petition.

Together we will make a difference!
Danielle Malchano, a wound care expert from National Rehab, a nationally recognized leader in the provision of healthcare products, will answer questions on wound care products and procedures.

Dr. Noah Craft will discuss how physicians can improve diagnostic accuracy using the visually-based decision support tool VisualDx – a tool that could reduce P/P patient diagnosis times and is something you won't want to miss! And

Michelle Greer, Vice President of Business Development, Chronic Therapies from Crescent Healthcare, Inc., providing home infusion services to patients with chronic disorders, will be available to talk to patients about intravenous therapy.

AxelaCare, a national specialty infusion pharmacy, will have its Insurance Advocates available to consult patients to help them get advanced treatments through specific insurance companies. For more information, see page 4's Annual Meeting Exclusive Action! Event or email molly@pemphigus.org.
CONGRATULATIONS TO MARC YALE on winning the IPPF’s 2009 AM Scavenger Hunt. Marc will receive one round-trip ticket to the meeting, a two-night stay at the Hyatt Regency Century Plaza Hotel, admission to the Annual Meeting, and an invitation to our Gala Celebration Dinner.

Congratulations Marc and thank you to everyone who entered!

Hi Everyone!

Like most, I remember that day very clearly. The phone rang, it was my doctor. She asked me if any of my other doctors had notified me yet about my test results from my biopsy. She told me that I tested positive for Bullous Pemphigoid. There was a long silence, then I thanked her and hung up. I hurried to my computer and began typing in those words my doctor had uttered just moments earlier. I don’t think I even spelled it correctly but after making the proper corrections one of the first items that came up much to my astonishment was the International Pemphigus Pemphigoid Foundation. I was surprised, not only had I just been diagnosed with an unusual disease but there was a whole group dedicated to people like me with the disease! I immediately registered and began exploring the website. The more I explored the more I learned. I was scared but just knowing that I was not the only one out there somehow made me feel a little better.

The Foundation has been not only an amazing resource for me but been a source of comfort and community. I don’t think I could begin to express how grateful I am to everyone at the IPPF. I was very fortunate to be able to attend last year’s Annual Meeting in Dallas and not only learned immensely about Ocular Cicatricial Pemphigoid but also had the opportunity to meet some very special people. That is why I was very excited when I was informed that I had won the IPPF Scavenger Hunt. I look forward to the learning about the latest news concerning my disease but also being able to meet everyone who share this very special connection with.

See you in L.A.!

Marc Yale

“Whether I win or not I have spent the past 6 hours learning a lot! Thank you for all the info you put together for all of us.”

-MaryLou
A major problem physicians and patients face when deciding on the treatment of rare diseases such as pemphigus and bullous pemphigoid is deciding on the best course to take. The decision is difficult as it is best made on the basis of objective evidence that the selected treatment works, and that evidence is sparse. The best objective evidence that a treatment is effective is to conduct a randomized trial, in which two or more treatments are compared head-to-head. Unfortunately, as bullous diseases are rare (which is a good thing), very few randomized trials have been conducted.

But there is another problem, which is rarely appreciated. It is that even when a randomized trial is conducted, the conclusions may not be clear. The problem is illustrated by a recent randomized trial in which the effectiveness of mycophenolate mofetil (CellCept®) was compared to that of azathioprine (Imuran®) for the treatment of bullous pemphigoid. All patients were also treated with systemic steroids. The physicians need to be commended on conducting the trial - it is one of the very few randomized trial in this disease. Their conclusion was that mycophenolate mofetil was preferable to azathioprine because it was similarly effective but less toxic.

However, the opposite conclusion can be drawn from the same data —that azathioprine is more effective and overall just as safe as mycophenolate mofetil. The time to induce complete remissions, the cumulative dose of steroids used, and the duration of remission were all better in patients treated with azathioprine than in those treated with mycophenolate mofetil. The average time to induce complete remission was 50% shorter, the time to induce remission in 100% of patients was 3 times less, the cumulative dose of steroids used was 15% less, and the duration of remissions was 30% longer in patients treated with azathioprine (n=38) that in those treated with mycophenolate (n=35). While these differences were not statistically significant, because the number of patients was small, the trend points to azathioprine as the more effective drug.

The authors also concluded mycophenolate mofetil was a safer drug because it was associated with fewer liver toxic effects. However, infections were more common in patients treated with mycophenolate and the overall number of serious side effects (grades 3 and 4) was similar in both groups; i.e. 11 serious adverse events in patients treated with azathioprine compared to 13 in those treated with mycophenolate mofetil.

What to make of these different interpretations of the same data? That even the results of randomized trials need to be interpreted carefully. In this trial, where the same data can be interpreted differently, there probably was little difference in the efficacy or safety of azathioprine and mycophenolate mofetil as adjuvant therapies for the treatment of bullous pemphigoid. A more fundamental question is whether either of these drugs provides a benefit over the use of only systemic steroids in the treatment of this disease. A randomized trial is needed to answer this question.
conscientious student, Amanda started high school academically behind. She felt isolated, scared, and angry. Yet, as she said in the paper she wrote in eighth grade, she lived life to the fullest, did not dwell on the negative, and soldiered on.

Amanda’s high school years have been very different than what I dreamed they would be before PV. I would never wish this disease on anyone, but I have to say that in some ways, her life is fuller, richer, and more balanced because of it. She is incredibly compassionate, perseverant, and is wise beyond her years.

Amanda is now a junior in high school, and has begun the process of choosing the path for the next phase of her life. She wants to go to college, and study either medicine or education. She takes 3 mg of prednisone every other day, and 2000 mg of CellCept® every day. Side effects are minimal.

PV is something Amanda has, but it is not who she is. For her senior project, Amanda wrote, a paper entitled "The Case for Continued Public and Private Commitment to Rare Disease Research and Development" [Editor: See her paper on our website at www.pemphigus.org/amanda]. Her research made us all aware that her disease is one of thousands of rare diseases, and how very lucky we are that hers is manageable and that we have the support of the IPPF to help us.

As Amanda’s mom, I never let my guard down. I mourn that her life is not care-free like a teenager’s should be. I live in fear of another flare. And I do worry about what will happen if and when she decides to have children and has to stop taking CellCept®. But I take my lead from my strong, courageous daughter, try to live one day at a time, and be thankful for our blessings.

Wendy Staso

Open communication is the most important tool in managing the school situation. Each school year, I meet with all of Amanda’s teachers, counselors, and the school nurse to explain her situation and put in place mechanisms should she have to be absent for extended periods of time. Normally, a student has to miss two weeks of school before home schooling can begin. For Amanda, if she flares, the school has arranged for home schooling to begin immediately. Likewise, if she is having a minor flare, but still goes to school, I email her teachers so they know that all is not as it should be.

Not only has Amanda’s disease affected all of us—my husband, son, myself, and most of all, her—but it has changed the course of all of our lives. It is thanks to our extended family and friends that we have coped as well as we have. I never hesitate to ask for help. Whether it is medical research, prayers, or just a hot cooked meal, we are surrounded by a network of people who love us and generously offer their special gifts to help us through the difficult times and celebrate the victories.

Since PV is so rare among the general population, and even rarer among young people, finding a dermatologist with experience treating it was not easy. We found Dr. Anhalt through the IPPF, and were quite willing to make the 3-hour trip from Pittsburgh to Baltimore to see him. My concern was what to do if Amanda had an emergency illness. I couldn’t go to Baltimore every time she got a cold. So I worked closely with Amanda’s pediatrician, Dr. Paul Trainer, and Dr. Anhalt, putting them in contact with each other, and with me, via email, so that we are a three-person team managing Amanda’s health.
Making a Difference in the Lives of Canadians

The Canadian Pemphigus and Pemphigoid Foundation (CPPF) is committed to making a difference in the lives of Canadians both locally and nationally. At the local level, we are deeply committed to establishing and helping to sustain as many support groups across the country as possible. We are pleased to report that in addition to our Toronto and Ottawa groups, we now have groups in Montreal and the Kitchener/Waterloo region. We have also started actively searching for group leaders in Calgary and Edmonton.

Our support group program – also known as the Circle of Friends Program - focuses on ensuring that patients and their families and friends obtain the emotional support and information that they need. Most meetings have a local expert (e.g., dermatologists, nutritionists, wound care specialists, etc.) speak so that patients can get the latest information and expert advice on treating and managing their condition. Meetings also have an “open forum” where patients and their families and friends can share their experiences with one another.

Visit the Foundation’s website at www.pemphigus.ca for information about upcoming meetings or for information on a support group near you.

The Foundation is also pleased to have become an affiliate of two very important organizations: the Canadian Skin Patient Alliance and the Canadian Organization for Rare Disorders.

The Canadian Skin Patient Alliance (CSPA) is new organization comprised of individuals and patient groups who are suffering from one or more skin conditions. Established in 2007, the CSPA is a patient-centred organization serving to enhance care, promote skin health and find cures for Canadians with skin conditions. Two priorities that are of great interest to us are increasing the number of dermatologists in Canada and working for additional training for non-dermatology physicians and nurses. By working with the CSPA on this issue and others, we hope to make a difference in the lives of not only our patients but all Canadians. Please consider becoming a member (it’s free!) and support their efforts through your participation. For more information visit their website at www.skinpatientalliance.ca.

The Canadian Organization for Rare Disorders (CORD) is Canada’s national network for organizations representing individuals with rare disorders like ours. It provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. A rare or “orphan” disease is a disease that affects fewer than one in 2,000 individuals. Currently, there are more than 7,000 rare disorders affecting over 3 million Canadians. The number of Canadians with pemphigus or pemphigoid is currently unknown. Our best estimate is that there may be as many as 4,000 of Canadians who suffer from these diseases. Most of our treatments are “off-label” (i.e., drugs being used to treat our illnesses were developed for other purposes). For example, CellCept® and Imuran® – two common drug therapies – were developed and are approved for transplant patients. For individuals suffering from a rare disorder, improving access to medications is critical and CORD and its affiliate members are working on making changes in this area. For more information about CORD, visit their website at www.raredisorders.ca.

Visit our “Canadian News” webpage for regular updates on how these two very important Canadian organizations are doing and what you can do to help.

If there are other issues that you would like us to investigate, visit our website at www.pemphigus.ca, or drop us a line at support@pemphigus.ca.
When the economy was crashing, I held my first fundraiser/awareness gathering – knowing that a majority of the invitees were retirees. I'd never done anything like this before, but people who know me know when I believe in something, I am clear about it. I believe:

- in the IPPF and our ability to improve the quality of life for those who suffer from P/P
- in science, research and the art in between to craft a solution to the rise of autoimmune diseases as a whole
- in the generosity of others and their interest in investing in making our world a better place

Ultimately, I know that most people are like me. When I see suffering, I need to help and I feel privileged to do so. Let me make you some chicken soup because it might warm your belly, but it certainly feeds my soul.

So my Mom invited scores of friends who might be interested. I speak publicly as a teacher-librarian; but in this role, the challenge was to talk about my own struggle, not how to search or evaluate. I lack confidence in that, but did my best. IPPF BOD Member Marcia Pepper told her story and IPPF BOD President Dr. Dave Sirois filled in the medical blanks.

Sixty attendees learned about P/P. In the disparate crowd, one woman's son had pemphigus, one woman's husband (a doctor) had written about a pemphigus patient over 20 years ago and one woman had a friend who had died of the disease. By the time we parted, this was a gathering of family—now educated about the disease and the hardships of those suffering chronic illness exacerbated by rarity and ignorance. It was the first time most heard the term “Ultra-Orphan”.

I asked attendees to think about the cause—not rush out and donate, but to consider it. I was touched by the response. Beyond the money donated to the IPPF in the days to follow, the outpouring was amazing. Every time my Mom goes to the store, someone asks about me or tells a story of someone who knows someone who...

I want to thank you. Reading this, you are a fellow patient, a doctor, or an interested friend or donor. You inspired me to overcome my fears and branch out so I could teach others about P/P. Anyone can do that. And I encourage you to try something new in a year when every non-profit is predicting dismal budgets. You have the power to change the world, one person at a time. Host a game night. Go to lunch with a friend and have them pass a pamphlet on to a doctor or dentist instead of tossing it. Like the butterfly whose flapping was felt in far off lands, make connections. They count.

My Mom recently told me the story of an attendee who was talking with a friend in Israel. The Israeli was suffering from a rare disease. Once described, she recognized the story and suspected it was pemphigus. It was.

Imagine the number of people diagnosed that have never met a single person familiar with pemphigus, including many of their own medical practitioners. Because of our work, one less patient feels alone at the beginning of her journey.

It is the six degrees of separation that brings us together.

Get Ready for the PEM Friends' Away Weekend

If you are interested in a relaxing weekend getaway, perhaps in the scenic Ashton-under-Lyne countryside, consider spending it with the PEM Friends (UK) June 27-28, 2009. Hosts Raymond and Carolyn open up their beautiful inn and stables to P/P patients and their families in Westerhill, Ashton-under-Lyne in the County of Greater Manchester. The Stables is available as early as June 22nd people would like to make a holiday of it!

On Friday, June 27, Carolyn will prepare an evening meal. She will also have plenty of food and drink for anyone to make a meal or snack for themselves at any other time.

On Saturday, there will be a ‘Gala Dinner’ in the main house and guests are encouraged to dress up for this occasion.

The Stables is a business and a donation of £10/per night, plus a £10 donation for the ‘Gala Dinner’, while not required, is greatly appreciated.

For more information, visit www.pemphigus.co.uk, call Carolyn at 0161 343 7100 or 07831 349978, or email carolynblain77@hotmail.com.
Nobel Prize Winner and PV Patient Passes Away

It was with great sadness that I learned of the December 2008 passing of Harold Pinter, one of the world’s leading playwrights. Harold, 78, was a highly respected actor and poet in the UK.

Years ago, after learning that Harold Pinter had pemphigus vulgaris, and prompted by some on the IPPF’s discussion group, I wrote to him.

It was a very carefully worded letter, knowing he must have been accustomed to getting many requests for help in different ways. I explained that we’d never want money from him, but just the honour of having him as the Patron of PEM Friends (UK). He replied immediately – by email, agreeing to become our Patron. His email was short and to the point, and that has been the extent of our communications. What a great man to have agreed so readily.

His passing is such a loss to us all.

Carolyn Blain

Find out more about him at www.haroldpinter.org

IPPF Adds New Section to Website Focused on News and Information

Recently the IPPF added a News and Information section to your website, www.pemphigus.org. This section contains information compiled from internal and external sources such as press releases, clinical trials, and frequently asked questions.

You can read more news by visiting www.pemphigus.org/news and staying up to date on what is happening in the P/P world.

LATEST STORIES:
- Interventions for Pemphigus Vulgaris and Pemphigus Foliaceous
- The Case for Continued Public and Private Commitment to Rare Disease Research and Development
- Explaining Your Autoimmune Disease (AID) is not AIDS
- Use of Infliximab for the Treatment of Pemphigus Vulgaris
- and more!

www.pemphigus.org/news
MEETING REGISTRATION

NAME: ___________________________________________________________ AGE: _____________

ADDRESS: __________________________________________________________________________________

CITY: ____________________________________________  STATE: __________________ POSTAL CODE: __________

COUNTRY: __________________________________________

PHONE: ______________________________________________________________________________________

EMAIL: _______________________________________________________________________________________

DISEASE: ______________________________________________________________________________________

NAME (as you want it to appear on your Name Badge): _________________________________________________________

☐ I require special assistance

(please attach a written description for all persons with special needs)

Please list names of other guests who are attending as you want them to appear on their name badge.

Name ____________________________________________ Special assistance? ☐

Name ____________________________________________ Special assistance? ☐

Name ____________________________________________ Special assistance? ☐

☐ I request scholarship assistance. Please call me and accept this partial payment to help defray costs.

TOTAL DUE $________

Check ☐ Money Order ☐ Visa ☐ Master Card ☐

Card #: ____________ - ________ - ________ - ________ - ________ Expiration Date: _____ / _____ Postal Code: ____________

Name on Card _________________________________ Signature _________________________________

Please make my tax-free donation in HONOR / MEMORY of _________________________________

(circle one)

☐ Please notify them at the following address:

ADDRESS __________________________________________________________

CITY ______________________ STATE _________________

POSTAL CODE ___________ COUNTRY __________________

Send payment in full to:

IPPF 2009 Annual Meeting
2701 Cottage Way #16
Sacramento CA 95825

or fax to (916) 922-1458

ALL PAYMENTS MUST BE MADE IN US CURRENCY AND MUST ACCOMPANY THIS FORM.

12th Annual Patient/Doctor Meeting - Los Angeles, CA, April 24-26, 2009
IPPF Website Wins Second Gold Triangle Award

The American Academy of Dermatology has announced that the International Pemphigus and Pemphigoid Foundation is a 2009 recipient of its prestigious Gold Triangle Award given for its patient website, www.pemphigus.org. Will Zrnchik, Director of Communications, accepted the award on behalf of the IPPF at the AAD’s annual meeting in San Francisco in March of 2009.

The IPPF informational website was recognized for the second year in a row by the AAD for its ability to raise awareness in the public and professional communities as well as the site’s overall design and content. In 2008 the IPPF won its first Gold Triangle and four MarCom Awards for its websites and newsletters.

American Academy of Dermatology Gold Triangle Award Winners are judged by a committee of Academy members and chosen based on specific criteria which include:

- Raising awareness of dermatologic issues
- Creativity/originality
- Medical accuracy/quality of information
- Enhancing awareness
- Helping change public perceptions

If you would like more information visit www.pemphigus.org/news.