Annual Meeting Recap!

by Miki Pangburn

If you turn on a light switch for a room to illuminate it and then the television, do they both use the same energy of electricity? The answer is no, they do not.

It felt as if a small village illuminated with full power at the Annual Patient/Doctor Meeting held at the Sheraton Society Hill Hotel in Philadelphia. When I arrived, my room was ready and I grabbed a slice and did some quick sightseeing with Janet [Segall, IPPF Founder]. Philadelphia is historic on its own; the crack in the liberty bell like the crackle of electricity was something to be in awe of. When you combined the location, the group of rarities that we all are, and the wonderful speakers and sponsors, I have to tell you, popcorn was popping! What a way to get in the mood!

Speaking of sponsors, a heartfelt “Thank You” goes out to Centric Health Resources, AxelaCare, Crescent Healthcare, National Rehab, and Alwyn Cream! Their continued support helps meetings like this one reinforce the Community concept!

Friday night’s mixer was very relaxing. Those in attendance could mingle with each other, the doctors, the sponsors, Molly [Stuart, CEO] and Will [Zrnchik, Director of Communications]. I chose to sit with a small group of women for a bit then went from table to table and began just asking people who they were.

One big table had me repeat the names, and I did pretty well until the last one. I blamed it on the prednisone. I introduced some to others that were

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Last year we addressed personal patient support needs with the Health Management Program (HMP). If you need personal support managing your disease, have specific questions, or want to discuss options with someone who’s been there -- you need the Health Management Program -- and a relationship with one of our Peer Health Coaches (PHC). (see Dr. Sirois article on the demonstrated benefits in improved heath from participation***). Let us know, we can set you up.

The Registry is an animal of a different stripe. In the Registry, instead, we need something from every one of you -- we need your data -- all confidential, of course (read more about our Registry’s privacy policy at www.pemphigus.org/registry-terms). Not "we" so much, but P/P patients of the future. For the benefit of the future collective of P/P patients, we need you to complete the registry -- launched at the AM. 1,000 records in the registry places us in position to ask for funding to support a research grant, inspire a scientist to conduct research, or provide data to move drug company developments in treatments.

We will be sending every patient we have email contact with a unique log-in to privately enter your information from your personal computer. Please, take the 15 minutes or so to document your experience and illuminate the urgent needs of this community -- for awareness, resources, scientific discovery and everyday solutions. Last year we asked you to dig deep to help us leverage the opportunity for a matching grant of financial support. This year we need to dig deep to make the collective of your voices and experiences heard -- for everyone’s progress.

We are at an exciting milestone, providing proof of the burden of disease and the path to discovery of effective new treatments. Please dig deep, once again -- this year with your time -- to support this community.

If you do not, who will?
JUNE
26 What Every American Needs to Know about Autoimmune Disease
Sponsored by AARDA
(Boston, MA)

JULY
17 What Every American Needs to Know about Autoimmune Disease
Sponsored by AARDA
(St. Louis, MO)

AUGUST
4-8 American Academy of Dermatology (AAD)
Summer Meeting
(Chicago, IL)

SEPTEMBER
18 What Every American Needs to Know about Autoimmune Disease
Sponsored by AARDA
(Cleveland, OH)

27-29 Centric Health Resources’ Ultra Orphan Conference
(St Louis, MO)

OCTOBER
26 American Skin Association 12th Annual Gala
(New York, NY)

NOVEMBER
5-6 Pemphigus & Pemphigoid: From Bench to Bedside
-medical professionals only
(Bethesda, MD)

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Thank You to our Supporters!

The following people made donations in February, March, and April 2010.
You can donate at any time by visiting www.pemphigus.org/donate.

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I wanted to let you know that I took some advice from the 2010 Annual Meeting! When I came home, I had an appointment with my oral surgeon at the University of Michigan. I was discussing the meeting with her, when I asked if there was any way I could speak about my disease at the dental school. She’s a specialist in pemphigus, but if I could present my experience and disease to the school, then one of the dentists may remember something that could help their future patients suffer less. My doctor couldn’t believe that I would be willing to come to the school! She is looking to see what date would be best and would like to take me on rounds at the University of Michigan Hospital.

This is proof how one person can make a difference. Thank you for giving me the knowledge and information to share my experiences with others. Hopefully, what WE do today will help others tomorrow!
Just Like the Name Says: promoting better health for those with P/P through the IPPF's "Health Management" Program

Three years ago a joint task force of the IPPF comprised of expert members of our Medical Advisory Board, Janet Segall (IPPF Founder) and Centric Health Resources (a Missouri based company dedicated to improving the quality of life for people nationwide with rare, orphan, ultra-orphan, and chronic genetic disorders), conceived and developed a Health Management Program (HMP) with the goal of improving illness experience through providing patients with educational resources, personal support and improved access to doctors and medicines. How did they decide to make all that happen?

The Model

The model looks like this: Trained and experienced Peer Health Coaches (PHC) perform an initial lengthy survey about a person's current state of disease -- are you a newcomer just getting control, or a long-timer who is getting more flares, or are you celebrating REMISSION!? Which medications are you taking, etc. Then each person has the opportunity to discuss specific questions -- what are the side effects of Dapsone, for example, or what can I apply locally to ease mouth blisters and sores? Finally, Peer Health Coaches send you any information that might help you move forward to making good choices in your best care -- nutritional info, the importance of monitoring your bones, or a list of expert P/P doctors in your area.

The key ingredient is PERSONALIZED education with the support and "touch" of a Peer Health Coach. Since the model for working with patients to improve care, through the use of peer patient/coaches who know what your going through, we launched enrollment and collected data on 127 people.

What have we learned and accomplished?

Well the basics show that of those surveyed, 58% were diagnosed with pemphigus vulgaris, 11% mucous membrane pemphigoid, 15% pemphigus foliaceus, 15% bullous pemphigoid and 1% paraneoplastic pemphigoid. The majority of people participating in the HMP enrolled with recent diagnosis, 2 years or less.

Molly Stuart, CEO of the IPPF, says that this tracks what is reflected in patients contacting the IPPF, at least 60% of new contacts are people who have been recently diagnosed and are trying to learn enough to insist on quality care.

To begin to look at trends, we focused on data from those who had participated with the Health Management Program in the initial survey and had done at least two follow-up assessments; a total of only 31 out of 127. Nevertheless, it is encouraging to see what is revealed.

Knowledge Improvement: There was a significant IMPROVEMENT in illness knowledge, in fact, NO patients continue to rate their knowledge of P/P "poor" or "very poor" after participating in the HMP process over this time.

Ability to manage illness: Again, people felt that they had significantly improved in managing their illness. Here also, NO patients continue to rate their ability to manage their illness as poor or very poor, unlike before they participated.

There was also a significant improvement in knowledge regarding their medications. Thirteen percent of those who had participated...
You can make a difference for years to come! Click on the link in your PERSONAL EMAIL invitation. If you didn’t get one, please call or email your Peer Health Coach or Will at will@pemphigus.org.

You can also participate by visiting www.pemphigus.org/registry.

Hurry! Time is running out on Dave’s challenge!

THE FIRST 100 PARTICIPANTS RECEIVE A FREE JAR OF ALWYN CREAM!
At the 2010 Annual Meeting in Philadelphia there were many patients and doctors who have consistently attended the meetings as much for fellowship as for information, as well as patients who were newly diagnosed and needing basic education on pemphigus/pemphigoid. Anyone who has attended these “marathon” weekends knows first-hand how much information is disseminated through lectures, expert panels and town meetings. It can be a bit daunting and always takes time to process, in addition to being exhausting. From past conferences, it has been my experience that by Sunday morning most people have left or are mentally unable to comprehend any more. It was a pleasant surprise this year to find so many still present on Sunday and eager to learn more!

This year I facilitated a group which allowed patients time for face-to-face interaction allowing them to talk in a more conversational way. I was privileged to talk with (not at) other patients with P/P at a breakout session on Sunday morning.

The purpose was to allow patients to share their experiences with each other. Instead of sitting in a panel or conference style, we arranged the chairs in a circle to make the room more conducive to a conversational experience. My purpose was more to guide the group than to “present”, since our experiences have consistently shown that people need to be heard as well as educated. What patients learn from each other is often more important than what can be learned otherwise. Lifelong friendships are made and validation occurs.

Those who attended this session were different ages, nationalities and genders; we also had patients with years of experience and those who were recently diagnosed. In addition, several caregivers also attended.

Once people started to introduce themselves and talk about their experiences, the energy level in the room just took on a life of its own. People started to identify with others’ experiences, and the group dynamics changed. This year, we were scheduled for one hour, and fortunately no one threw us out when we went past our allotted time. Will, in his own "Will way", did let us know this could happen at any time -- but it didn’t. Thanks Will!

Smaller groups of people began to talk to each other more toward the end, as they related to each other’s stories and experiences in getting diagnosed and treated and could share their own similar experiences. Since this was the purpose of the session, I was pleased that we had met long enough for that to occur. I also gave patients in attendance some inventories to complete on their own to give themselves a better idea of the psychological/emotional toll that these diseases can and do have on both patients and caregivers. A few people have since let me know how helpful it was for them to have words to describe the way they are feeling.

As I told the group in attendance, if someone walked into my psychology office and told me that they had received one of these diagnoses and that they were just fine I would want to know how that could be. The only defense mechanism which allows people to not be affected emotionally is denial. There also remains a number of people who are unaware that the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM) does recognize that patients’ emotions can be affected by certain illnesses (e.g., 293.83 – Mood Disorder Due to…[Indicate the General Medical Condition]).

As some with alcohol problems have discovered, Alcoholics Anonymous (AA) allows people to become -- and stay -- clean and sober by having meetings and sharing stories. Since it is so helpful to talk with others with the same diagnoses but different stories, I have begun to wonder if we may want to begin thinking of our own Twelve Steps. Just a thought…

Remember to take care of yourselves and to not give up hobbies and activities that have provided joy in the past, unless you are no longer able to do them because of your health. And, if that is the case, try to find a substitute hobby or activity to keep joy in your life. This may be challenging, but it is absolutely necessary for your mental health. Stress takes an enormous toll on our physical health, as well as our mental health, so continue to work on more positive coping strategies.

If you need help with this, do not hesitate to ask for it.

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.
in search of answers to some questions. I sat back and observed the camaraderie of the group. Intense conversations and laughter filled the air. Will was on spot when I whipped out my camera – as if on cue, he turned his head and smiled.

Saturday's breakfast was magnificent, and I felt so much better once I had my café mocha with a shot of hazelnut. Oh, I was a happy little camper and ready for anything with a big old smile on my face. Everything seemed as if it was in its own perfection. The booklet with the weekend layout was great in the sense that you could follow along. I sat in the back, listened to Dr. Grant Anhalt's presentation, and understood it. Please allow me to take a moment and thank whomever it was that came up with the idea of espresso in the morning before medical doctors and panels spoke. I believe Gloria Papert did an excellent job of keeping the times allotted for speaking. She is such a jovial woman; you could not help but smile when she spoke to you.

The breakout sessions were clearly marked, and I chose to listen to NDRI, which stands for National Disease Research Interchange. A lot of interesting information on donating tissue and blood samples that is extremely important in order to one day have a cure. I grabbed a booklet, but have not had time yet to fill out the information. I, for one, am totally for this. My skin comes off with the PV any-thing of the sort, but it meant a lot. I just have a gift of gab. Somewhere I can hear my mother telling me to keep quiet, but she is smiling in her heart.

When lunch was through, Dr. Ani Sinha gave a very informative lecture on Why Do Patients Have Flares? This was my second cup of espresso, and it kicked in during his question and answer session. Dr. Dave Sirois had a breakout on Oral and Dental Care. Something interesting with Dr. Sirois... During the raffle, he whipped out about a dozen tickets. That was ok, except I noticed he did not put the other halves in the boxes. Therefore, I informed him of this and his statement was, “Well that explains why I never win anything!”

Saturday evening was "on your own" or a movie night, many people decided to go out, which was nice. I ate dinner with a small group and enjoyed their company immensely. I love to hear stories as well as tell them. Brian Cleary from AxelaCare was like a personal map/tour guide because Philly is where he lives.

I felt for Will, he was running around like a mad man all weekend and his coffee was usually cold. He gave up his animal printed tie to me to add as a band for a sundress I am making. He just had to explain it to his other half. Wonder how that went… ;)

Anyway, bottom line is that the lights did not go out. With a walk to Penn’s Landing to see the old masted ships in the harbor, I went back to the hotel and had a “special” decaf nightcap. Unfortunately, I had to leave early Sunday to come back to my family. It was nice to run away for a weekend, and to share something that so few of us know.

To my other family, thanks for the laughs, the conversations and the fun. You are the entire "crack in my bell" -- but the electricity is what keeps us connected.
surveyed stated that they started the program with what they considered their own Poor/Very Poor understanding of meds and at this point, NO ONE reports such lack of knowledge about medicines.

Another measure of understanding is in the area of what doctors call "compliance" (i.e., willingness and ability to take the medicines prescribed). This also improved significantly.

When people first started the HMP, over 60% reported that they had “often been bothered by feeling down, depressed, or hopeless” in the last month. Upon further participation in the HMP, this was reduced by more than half -- to slightly over 25% feeling that way still. This is where the work of local support contacts and Peer Health Coaches really shines. Email Molly (molly@pemphigus.org) or Marc Yale (marc@pemphigus.org) to find out how you can serve.

Finally, we see that patients are also getting better care related to general health promotion and disease prevention. More patients got bone density scans and more patients monitored their blood pressure. They also better understand the detrimental risk factors for patients on many of these medicines.

Increased patient confidence! Increased patient knowledge! Increased medication compliance! Improved preventive and routine testing! Better quality of life! NOW you see why we called it "Health Management"!

If you want to improve your health experience by participating in these ongoing surveys and being teamed with a Peer Health Coach, visit www.pemphigus.org/hmp or contact Marc at marc@pemphigus.org. Good evidence that HMPs really do improve health, make this an important part of the services that the IPPF provide for patients; knowledge, health, support and hope.
I’ll wager that when your automobile’s “check engine” indicator flashes on, you quickly get your car into the repair shop. So why, when my personal “check engine” light flashed, did I ignore it? When I was diagnosed with Pemphigus Vulgaris at the age of 47, the first information I unearthed regarding the disease was at my local bookstore. It was there, sitting cross-legged on the floor, that I found one medical book that referred to pemphigus as “a blistering disease that is usually fatal.” Ha! Fifteen years later, I’m alive, and usually well, excepting the occasional flare. But that doesn’t mean the road I’ve travelled hasn’t been without its potholes. Thanks to my doctors, my family, and, finally, the IPPF, I’m up and running, ready to coast through the next 15—or 30!—years.

When I first became ill in 1995, I was fortunate to have been diagnosed quickly—only 4 months from start to finish. I had great doctors who, by the way, had never seen or treated pemphigus. I take that back. My dermatologist had seen one case while in medical school but that patient died from her PV shortly afterwards. To say that my doctors were big ‘fraidy cats would be an understatement! I was placed on 20 mg of prednisone—too little to do any good.

It took some research (remember, 15 years ago the internet was an infant) but I eventually discovered the perfect PV mechanic in Janet Segall, who at that point was working out of her house to help others with pemphigus, some 3,000 miles west in California. Janet was a fountain of information and, after several discussions, she suggested I make an appointment with either Dr. Jean-Claude Bystryn at NYU Hospital or Dr. Grant Anhalt at Johns Hopkins, since they were both within a manageable five hour drive from my home.

I chose Dr. Anhalt and was given an immediate appointment. What a relief! He reassured me that I was not going to die, and that I was not contagious. I remember thinking: “Really, I can kiss my baby grandson?” Back home, we got down to business. Under Dr. Anhalt’s direction, my family doctor and dermatologist worked together and ordered baseline tests for bone density, a thorough eye exam, blood work, chest x-rays—you name it, I had it. Their close observation resulted in a wonderful ten year remission. Trust me, I was a perfect patient—until 2005, when I was promoted into my dream job.

I put pemphigus on the back burner, and my job on the front burner. I worked 60 hours a week and travelled constantly. But within two years, my tank was empty. I was exhausted, developing harsh colds accompanied by fever, coughing spasms, and severe laryngitis that silenced me for weeks. Eventually, I would regain my health, get on with life and wait for the next onslaught.

One morning, I woke to discover a bloodstain the size of a dinner plate on my hotel room pillow. I was startled but took no action. Several months later, it happened again on an international business trip. My expectant daughter, who was with me, was horrified. For her sake, I laughed it off: It’s happened before, it will be okay. She was not so easily pacified; daughters can be very tiresome creatures!

I should have known then that my personal “engine light” was flashing. But I ignored it. Unfortunately, the day after arriving back in the States, I experienced a searing chest pain and with one cough shredded five inches of my esophageal membrane. No siree, pemphigus was not ignoring me. It had found the perfect breeding ground and, now, my chassis was parked in the hospital.

I was released in seven days, not only reeling with invasive PV, but also as a newly minted Type II Diabetic from the massive doses of prednisone. Four days later I suffered a large retinal tear in my right eye and required two laser surgeries. I was terrified of what might happen next; it was a hideous state of affairs.

I was out of work for four months and used that time to seriously re-evaluate my lifestyle and the changes age had brought about. I finally acknowledged my reckless habit of undermining my health in what was a clear case of “dis-

I’ve learned my lesson: a tune-up is not an option; it’s a requirement.

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At the Annual Meeting a few weeks ago, and on the feedback forms that we received, a lot of people made note of how hard it is/was to follow along with all the acronyms that those of us immersed (in any subject) tend to throw about. This is especially true for people new to a group, feeling unfamiliar with the meaning of lots of new terms, but it seemed clear that many people are still wondering which IPPF program is most appropriate for their level of engagement with the Foundation and the "cause".

There are so many "jobs" to do in building a better experience for P/P patients: someone needs to tell doctors about the symptoms and treatments, someone needs to go show their wounds to interns and dentists, someone has to write newsletter articles, someone has to offer their expertise with different medicines and share their wisdom, someone has to accept help from those that have also suffered, in order to get better themselves. What can you do, that fits your needs and upholds the value of service and compassion for others on your path?

Know your Acronyms!

PPR: "The Registry" Here, P/P patients submit data on their disease activity and medicines. The form is online, you do it from home, anytime; takes about 15 minutes, one time. So, it's super easy in terms of what you have to put in, the catch (of course there is a catch to a sentence that starts with "super easy") is that we need AT LEAST 1,000 people to do this in order for that to be enough data to influence any argument for research or funding. Finding 1,000 PEMPHIGUS/PEMPHIGOID patients isn't so easy -- as you well know! We have a "job" that ONLY YOU can do. We need you to put your data in. Everyone of you. Everyone.

If this resonates with you and you have the energy to do more, then get the word out to every other P/P patient there is... ask your doctor if they will forward a link to the registry to others they treat; send requests to Dermatology Chairs at teaching hospitals; ask/remind your Facebook® Friends and encourage your Forum and Discussion Group buddies, if you have other ideas share them too, growing the impact even further.

HMP: "Health Management Program". The HMP is an over-time series of surveys of your current state on that day, combined with the opportunity to discuss these experiences at the time, with a Peer Health Coach (see below) who is there to advise you (and maybe even nag/inspire you) on advocating for your own best care with the best information currently available. They can weigh the pros and cons of different options, suggest everyday soothing strategies and forewarn you about things to be on the lookout for. They also will always stand by in helping you get the most out of your time with your doctor -- or suggest a better one. This program is a huge investment of the patient's commitment, the Coach's dedication and the mission of the IPPF. If you need better care, the HMP team is here to make it happen.

PHC: "Peer Health Coach" Peer Health Coach refers to another P/P patient who goes through an extensive training process -- on disease processes, medications and side effects, privacy security, and interpersonal motivation and support. This demonstrates the HIGHEST level of commitment that one can dedicate to the service of other patients, and is the culmination of moving through other patient support opportunities such as:

Peer Support Coach: You are interested in learning more about this disease, medicines, and are willing to do a little bit of online training on medical privacy and recording data about calls to help move patients to the right resources.

Support Contact: (Local or Disease Specific) Want to make yourself available to talk with someone who's seeking support in their geographic area? You may offer to allow the IPPF to give out your name, email or phone to others who want to talk to someone. It won't happen a lot, but you would then be relied upon to reply to this patient in need.

In the Health Management Program, rest assured the resources of knowledge, experience and expert doctors work to prepare you to handle your health better. When you enter your data in the Registry, you help others handle their health in the future by providing researchers and front line doctors information to pursue better treatments. Anything in-between just makes the support of our net wider -- we appreciate you doing what you can.
The Annual Meeting attendees were the first to receive their PERSONAL invitation to participate! If you have not received your PERSONAL invitation, contact your Peer Health Coach, or Will at will@pemphigus.org. Fifteen minutes is all it takes to make a difference!

We are determined to get a minimum of 1000 (plus a few to spare) “data-sets”. We need 1000 disease history/medication experiences recorded so that the numbers are (statistically) significant to define treatment opportunities.

This data will be used when our Medical Advisory Board (MAB) and P/P experts from around the world gather at the NIH in the Fall of 2010 to define consensus and advise on protocols.

All this data collection will be gathered in an online survey -- no phone calls, no appointments (unless you want), just log in, enter your meds, improvements and flares -- at midnight, in your pajamas, on your cell phone, whatever works for you. We appreciate what you contribute to helping everyone have access to better treatments!

INTERNATIONAL LINKS TO SUPPORT

CANADIAN PEMPHIGUS AND PEMPHIGOID FOUNDATION (CPPF)
http://www.pemphigus.ca

AUSTRALASIAN BLISTERING DISEASE FOUNDATION (ABDF)

ASSOCIATION PEMPHIGUS - PEMPHIGOÏDE FRANCE (APPF)
http://www.pemphigus.asso.fr/

ASSOCIAZIONE NAZIONALE PEMFIGO/PEMFI GOIDE ITALY (ANPPI)
http://www.pemfigo.it

NETWERK NEDERLAND VOOR PEMPHIGUS EN PEMFIGOÏD (NNPP)
http://www.pemphigus.nl/

PEM FRIENDS (UK)
http://www.pemfriends.co.uk

SPANISH FACEBOOK GROUP
http://tinyurl.com/ippf-facebook-es

If you have a group you let us know so we can help spread the word!

The IPPF P/P Registry Needs YOU More Than Ever!

The Quarterly www.pemphigus.org Summer 2010 13
ease to please” everyone but myself. I immediately made changes. I was now 58 and could retire with benefits at 60. My management and company medical department provided unconditional support. I gradually resumed my workload to a more-manageable 40 hours a week or less, and I no longer travelled. It was not unusual for my manager to stroll into my office at any time of day and direct me to go home. I loved him!

I retired two years ago this month (May). I set only a few goals. I would correct my six-year-old grandson’s batting stance, start a local Pemphigus support group, and refuse to engage in activities, social gatherings, or anything that did not enhance my well-being. I completely embraced my new freedom and after 28 years of “oh-dark-thirty” alarms, discovered the delight of waking naturally and savoring that first hot cup of coffee.

Along the way, I found my locality does not lend itself to a pemphigus support group; there just are not enough of us. So, I recently became active in the IPPF. I am now a Peer Health Coach so that I can “pay forward” the terrific support I have received from the IPPF. My grandmother, a depression-era medicine woman, would be so proud.

Although I was really too ill from a flare-up to attend the recent IPPF Annual Meeting in Philadelphia, I hauled myself there anyway. I’m so glad I made the effort! Going to the conference served as a huge wake-up call for me. It had been three years since I last attended a meeting, and I was delighted to hear of newer treatments, success rates, studies, wound care, etc. Break-out sessions on several topics allowed me to tailor my learning to fit my situation. Finally, I saw Dr. Anhalt there, and he once again has given me hope, and put me back on the path to controlling my flare-ups.

I’ve learned my lesson: a tune-up is not an option; it’s a requirement. So, just as you’d take your car in for annual service, make a plan to attend the annual conference next year. Consider it your personal, annual tune-up. The conference is a great place to network with physicians and professionals on the cutting edge, to ask questions of experts and receive down-to-earth answers from the people that “get” you. The forums are informal, open settings that allow everyone to absorb the information. The icing on the cake is the exposure and interaction with others who have walked the walk. I guarantee you will connect with someone with whom you will stay in touch.

In writing my story, I hope to encourage you to take advantage of the many wonderful opportunities the IPPF provides. We have at our disposal dedicated doctors, researchers, a physician referral list, clinical trials, and pictures and information available to become knowledgeable, articulate, and on par with (or ahead of) the physicians that treat us. Visit www.pemphigus.org and connect globally in forums and chat rooms with others who understand what you are experiencing. Through the Health Management Program, an email or phone call will put you in personal contact with a Peer Health Coach.

I am excited about the IPPF’s confidential and secure Pemphigus-Pemphigoid Registry! We will have the opportunity to register our personal stats, thereby drawing nearer to the common goal of a cure for the diseases and variants of pemphigus and pemphigoid. It’s heady stuff, on an international scale!

Contrary to the inadequate information I uncovered 15 years ago sitting cross-legged on the floor of a bookstore, the real message about pemphigus is one of hope, camaraderie, and medical advances. Come join me at next year’s conference to fuel up on all three!

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I retired two years ago this month (May). I set only a few goals. I would correct my six-year-old grandson’s batting stance, start a local Pemphigus support group, and refuse to engage in activities, social gatherings, or anything that did not enhance my well-being. I completely embraced my new freedom and after 28 years of “oh-dark-thirty” alarms, discovered the delight of waking naturally and savoring that first hot cup of coffee.

Along the way, I found my locality does not lend itself to a pemphigus support group; there just are not enough of us. So, I recently became active in the IPPF. I am now a Peer Health Coach so that I can "pay forward" the terrific support I have received from the IPPF. My grandmother, a depression-era medicine woman, would be so proud.

Although I was really too ill from a flare-up to attend the recent IPPF Annual Meeting in Philadelphia, I hauled myself there anyway. I’m so glad I made the effort! Going to the conference served as a huge wake-up call for me. It had been three years since I last attended a meeting, and I was delighted to hear of newer treatments, success rates, studies, wound care, etc. Break-out sessions on several topics allowed me to tailor my learning to fit my situation. Finally, I saw Dr. Anhalt there, and he once again has given me hope, and put me back on the path to controlling my flare-ups.

I’ve learned my lesson: a tune-up is not an option; it’s a requirement. So, just as you’d take your car in for annual service, make a plan to attend the annual conference next year. Consider it your personal, annual tune-up. The conference is a great place to network with physicians and professionals on the cutting edge, to ask questions of experts and receive down-to-earth answers from the people that “get” you. The forums are informal, open settings that allow everyone to absorb the information. The icing on the cake is the exposure and interaction with others who have walked the walk. I guarantee you will connect with someone with whom you will stay in touch.

In writing my story, I hope to encourage you to take advantage of the many wonderful opportunities the IPPF provides. We have at our disposal dedicated doctors, researchers, a physician referral list, clinical trials, and pictures and information available to become knowledgeable, articulate, and on par with (or ahead of) the physicians that treat us. Visit www.pemphigus.org and connect globally in forums and chat rooms with others who understand what you are experiencing. Through the Health Management Program, an email or phone call will put you in personal contact with a Peer Health Coach.

I am excited about the IPPF’s confidential and secure Pemphigus-Pemphigoid Registry! We will have the opportunity to register our personal stats, thereby drawing nearer to the common goal of a cure for the diseases and variants of pemphigus and pemphigoid. It’s heady stuff, on an international scale!

Contrary to the inadequate information I uncovered 15 years ago sitting cross-legged on the floor of a bookstore, the real message about pemphigus is one of hope, camaraderie, and medical advances. Come join me at next year’s conference to fuel up on all three!
Annual Meetings are More than a Patient-Disease Experience: Caregivers Get Support, Too!

This year’s annual meeting in Philadelphia was again a huge success because of the tremendous amount of information, knowledge, research and hope made available to patients and caregivers. It was also a family reunion for some of the regular attendees strengthening the bond and giving a “renewal of commitment” between existing patients. It’s really fantastic and encouraging event. It is a wonderful feeling to know that some patients in partial remission make the extra effort to attend these meetings thereby giving support to our new friends.

The different venues for the IPPF Annual Patient/Doctor Meeting give us an opportunity to visit different states each year. We really enjoy going to these conferences because it is such an amazing source of face to face interaction. We schedule attendance to the meeting as a family pilgrimage. It also brings back the core values and keeps us aligned with the reality of this disease. There is always something new to learn, and it’s all made possible by the great and generous people who have been working for us on our rare disease research projects.

As a patient, it connects to existing patients and also gives the opportunity to share successes and disappointments. After six years of trying to stabilize the disease, it gives a sense of confidence to be able to give advice and information to new patients. Knowledge is power and the more we learn about our disease, the more we would be able to handle and control our flares.

Knowledge is power

As a caregiver, it realigns the commitments necessary to continue to support your love ones and to share learnings to new caregivers.

We recognize and thank everyone involved.

Seepersad Babooram
Caregiver, Houston TX

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