Over 130 Attend Successful Science Meeting in Bethesda

Over the course of two information-packed days in November 2010, the IPPF, along with the National Institutes of Health (NIH) hosted its third international science meeting. The Jean-Claude Bystryn Pemphigus and Pemphigoid Meeting: From the Bench to the Bedside was sponsored by Crescent Healthcare, Centric Health Resources, Biofusion, Inc., and Talecris. The meeting was organized by Drs. Sergei Grando, Victoria Werth, Luis Daiz, and the late Jean-Claude Bystryn.

Dr. Bystryn passed away during the final planning stages of this meeting and the committee felt it fitting to name the meeting in his honor. Dr. Sergei Grando said, “Many of the doctors in attendance at the Science Meeting were folks who had worked side-by-side -- or in the footsteps of...Continued on page 5...
W
ow, another year has come to a close already, I bet you all feel both the relief and the
bittersweet feeling of time’s passage. We feel it here, too, so many advances were
made this year for P/P patients as we used the earnings from the Double the Difference
Campaign in 2009 to fund some major new initiatives in 2010, and yet there is so much
more we want to do.

This year our key projects included: the Annual Meeting in Philly. With many breakout
sessions on specialized targets, over 100 patients had small group facetime with doctors.
In addition, the PHC and IPPF staff helped over 1,000 new folks in 2010, connecting with
many patients through Facebook, now with around 200 “friends” sharing info, stories,
questions and advice.

We have expanded on our commitment to reach out Internationally. There are now sister-(I)PPF’s in Canada (CPPF), and in Japan (JPPF) and we have new partnerships with clinics in Venezuela, Italy and Germany. And
most of you know Carolyn Blain. Carolyn has generously agreed to advocate for new patient requests to us from the UK; and Janet Segall is offering a wide range of coaching and hypnotherapy techniques for P/P pa-
tients (and others with stress).

We are pleased to announce that the Registry has been translated to Spanish and we have several resourc-
es to help patients who are Spanish speakers.

W
 held our Third Science Meeting, named in honor of Jean-Claude Bystryn who was on the Steering comm-
itted and passed away this year. Over 130 medical professionals with a emphasis in P/P research and treat-
ment came together to share and debate information about fruitful areas of lab research and best practices.
They also shared with the IPPF the need for subjects who will participate in trials or donate blood for studies.

Finally, although we did not get 1,000 P/P patients to enter their data in the Registry before the meeting, the
doctors were very keen to explore what the results show regarding what treatments are actually helping peo-
ples the most -- something we have never known before -- so they are taking action to get their patients en-
rolled as well. Please take time over the holidays to add your experience, it will help so many!

Still waiting for us to accomplish in 2011... Raising funds to:
• translate the Registry - we’ve had requests for Persian, German and Italian!
• Raise Doctor’s Awareness Campaign for better diagnoses and treatment
• Bio-Bank donation and research study
• Treatment Best Practices Consensus Meeting
• More PHCs to server the over 1,000 requests we handle each year,
• and of course... The Annual Meeting! - Detroit, May 20-22, 2011

Most importantly, though, it is about people who have suffered and people who have comforted. There are
so many. Foremost, our Peer Health Coaches (PHC’s) Marc, Yvette, Susan, Sharon and Jack, located around the
country, ready to speak about their experience, medications, symptom treatment, science and drug knowl-
edge, and hope. And there are many more of you supporting others on your own, on Facebook, through the
IPPF Forums, working in your community to educate doctors and by donating to the IPPF to reach for the bigher goals -- funding research and gathering information through the Registry and tissue samples so doctors
can have real information about which drugs or combos work.

Please support the IPPF generously this year. We make sure that there are places for new patients to reach out, to get good information, to find a competent doctor, and to influence a cure, but we cannot do it with-
out you. Thank you.

Molly Stuart, JD
Chief Executive Officer
molly@pemphigus.org

From the Top

International Pemphigus & Pemphigoid Foundation
Thank You to our Supporters!

The following people made donations in August, September, and October 2010. You can donate at any time by visiting www.pemphigus.org/donate.


We make every effort to accurately recognize our donors. If you were omitted, please let us know so we can show our gratitude in the next issue.
Dear IPPF Community:

The Board of Directors wants to acknowledge the incredible success of the Jean-Claude Bystryn 3rd International Pemphigus & Pemphigoid Meeting, and especially how extraordinary it was for the preeminent, International P/P medical and scientific community to all come together in Bethesda for 2 days of intense and informative discussion on the status of science and therapy for autoimmune bullous disorders. Over 130 medical professionals participated, with speakers from Iran, Japan and Austria.

We thank Drs. Sergei Grando, Vicky Werth, and Luis Diaz for their tireless efforts in planning this spectacular scientific meeting. Molly and Will, thank you so much for all the effort you put into what was an absolutely spectacular meeting! YOU are Champions!

Gratitude from the whole P/P Community goes to all the speakers for their very thoughtful, informative presentations, the tremendous energy of their research and discovery efforts, and, of course, their work to summarize the "state of the field" so well. And, thanks to all the participants who judged the importance of this meeting and its learning opportunity so critical as to give up time in busy professions and away from family and friends to attend this meeting and contribute your collective wisdom to the rich dialogue we all enjoyed.

Integrated meetings such as these tighten the responsiveness between science and medicine and guide agreement and education on the best practises for effective treatment of P/P. All donors who supported the 2009 Double the Difference Matching campaign and special sponsors such as the National Institutes of Health (NIH/NIAMS), Crescent Healthcare, Centric Health Resources, Talecris and BioFusion deserve extra appreciation for the foresight and commitment that spurs their investment in the future of P/P patients.

David Sirois
President, IPPF Board of Directors
There was a touching rememberance of Dr. Bystryn given by Dr. Karl Holubar who traveled all the way from Vienna University in Austria. Doctor Holubar is is a professor of both dermatology and the history of medicine, and his career in investigative dermatology started with a series of exciting discoveries in pemphigus and pemphigoid immunopathologies, so he had much perspective to offer.

Next came a memorial announcement by Dr. Grando -- an obituary article remembering Dr. Bystryn was published by Experimental Dermatology. You can get a copy online at http://bit.ly/jcb-article.

Based on his 40+ years of experience reviewing grant applications and peer reviews, retired NIH scientific review officer Dr. Harold Davidson believes the outcomes from this meeting provide the attendees with points to build upon. He said, "They found out what they know, what they don't know, and what they need to find out."

"When planning this meeting, Jean-Claude, Vicky Werth, Luis Diaz and I worked to focus on practical implications/applications of pemphigus and pemphigoid research," said Dr. Grando. "The major goal achieved by this conference was demonstrating to all how discoveries of the mechanisms of pemphigus and pemphigoid can improve patients' well-being." It is extremely important to identify how innovations in the basic science reported at the conference can be used in a clinical scenario, even if such scenarios might appear purely theoretical at that point in time.

Over 130 medical professionals - both researchers and clinicians - gathered for the four plenary sessions with 30 key-topic speakers and 20 oral abstract presentations. Each session was divided into two distinct segments of focus: the “bench” (research in the laboratory) and the “bedside” (working directly with the patient). Dr. Grando was pleased attendees were able to debate: "We had sufficient time for free discussions at the end of each session, and the participants carried on a constructive debate challenging the dogmas." The IPPF hopes this type of communication leads to consensus and collaboration in the future.

When asked for his final thoughts on the meeting, Dr. Grando said, "It was wonderful to gather in honor of Jean Claude, to share knowledge with old friends, and to see such a commitment to all of our patients." Rest in Peace Jean-Claude.

If you would like more information on the registry, participating yourself, getting your doctor involved, passing the link to others through Facebook®, or sharing any ideas you have that may help, please visit http://www.pemphigus.org/registry or visit us on Facebook® at www.pemphigus.org/facebook. You can also contact the Registry Admin at 916-922-1298, ext. 1003.
The holidays and end of year are nearly upon us as I write this article. This time of year brings so many different and conflicted feelings for most people, usually very personal and emotional. As noted previously, while so many look forward to so much, many people have bittersweet memories and difficult standards and goals for which to strive during the holidays and into the New Year. It is a time for remembering activities and traditions of previous holidays but also the losses (health restrictions, jobs, lifestyle and people). For some there have also been improvements in health and treatments and new traditions. Others hold onto the more troubling thoughts and feelings and have great difficulty moving on. Sometimes the illness itself is not responding to treatment yet or is being stubborn and brutal.

Tears often represent unresolved sadness and grief, in addition to actual clinical depression. When living with chronic illness patients and caregivers can’t help but experience, a mix of depression and anxiety from changes in the status quo. After all, chronic illnesses don’t go away, which is why they are called chronic to begin with. Seeing family and friends, not seen often, during the holidays often brings people into the position of being seen as SICK and HELPLESS or being told they look BETTER and so must be doing/feeling better.

And, don’t forget that tears can be positive, too. I often tell patients that tears are allowing toxins to leave the body; who doesn’t want a less toxic body? People also cry when happy or just plain sentimental. I have one friend who never ceases to make me laugh. I keep telling him to take his act on the road!

Sometimes it is just easier to not discuss at all since “chronic illnesses” seems to be such a mystery to so many, especially a rare or ultra rare disease. One person I know actually carries around a few copies of the dictionary definition of chronic in order to avoid explanations. If there is loss of energy it may feel like running a marathon just getting together with family and friends, even when not trying to “host” the holidays or a get-together. Travel can feel like a triathlon; sometimes just getting out of bed, let alone the home, can be excruciatingly difficult.

Fears, Tears, and Hope -- and Cheers for New Years

The essential ingredient in getting through this is acceptance; think of acceptance as the main ingredient in the recipe. If unable to get to acceptance, try putting hurtful feelings on hiatus in order to get through difficult periods. I do not advocate pushing yourself beyond your limits, but one thing psychologists learned from the “behaviorists” (Skinner, Watson, et al) of the 1960’s is that one does not have to feel wonderful or have tremendous insight to effect changes: making changes, even small ones, can actually make you feel better. For example, just going to a gathering may make a person feel better, even if there is a need to leave early. Getting more dressed up, and seeing oneself in a mirror, allows the person to see themselves more as they once were and may again be.

Fears of the uncertainty of it all are real and often keeping anxiety high or ever-present. With chronic illness one never knows what the next day will bring. Expectations of what one can or cannot do may be unrealistically high or low. In either case, anxiety may remain a constant. Some people even have actual panic attacks, where they have trouble breathing and chest pain, simulating a heart attack. If on high doses of a medication like prednisone, life will feel like a roller coaster . . . because it is!

Continued on page 12...
The 2010 Science Meeting and How it Benefits Patients Everywhere

by Janet Segall

On November 5-6, I was a speaker and guest of the IPPF at the Jean-Claude Bystryn Pemphigus & Pemphigoid Meeting: From the Bench to the Bedside. The expertise on our diseases was very impressive, and it surprised me that I actually understood much of what the doctors and researchers were talking about. It saddened me, however, that Dr. Bystryn wasn’t a part of the conference. I truly felt his absence as did many of us there.

What impressed me the most was the commitment I saw and heard from these very interested and dedicated physicians and researchers. It was great seeing everyone communicating respectfully with one another -- even during a disagreement or the question and answer session.

I spoke on the "Patient Point of View" to keep the science in perspective for the doctors. It is so easy to get lost in the talk about specific molecules that make up cells, what their actions might be, how they might affect the immune system, etc. It is easy to get away from the "whys" of what it is all about, and who it is all about.

After all the science was discussed, I had a few minutes to talk to the group about the realities of being a patient with pemphigus or pemphigoid. I spoke about what patients need from their doctor when they walk into their offices. I told them that I understood the realities of having to cram in as many patients in a day; having possibly only 15 (maybe 20) minutes for each patient. But, I reminded them that it is important for the patients to feel confident in the doctor treating them because they are scared. The patients need to know that the physician is on their side.

I suggested to them that it helps the patient if doctors are honest about their time or lack of it, to explain to the patient that it would be in his/her best interests to have questions written down before coming into the office. In keeping up with honesty, I reminded them that if they don’t know something -- say so. I recalled what one patient said to me: how having a doctor say they "didn't know" made them feel okay and comfortable about trusting their doctor.

I really felt like I was heard and looking around the room, I noticed everyone listening. That said to me that they care -- they care about how patients feel and what they need. One doctor said to me at the end of the meeting, "Sometimes we do have to be more connected."

As a patient with pemphigus, I applaud what they accomplish through working together. I’ve been lucky that I have been able to keep my disease at bay for the last 11 years. I hope that one day someone will have an "ah ha!" moment and find that one or two (or more) things that will stop that signal from the gene which tells our own antibodies to attack ourselves.

I do believe that finding the answer to pemphigus -- or any one of the number of autoimmune diseases -- will eventually be the panacea for all autoimmune disease.

Until that time, I trust all of those very smart people in that room willing to treat us and work to find a cure on our behalf.

Janet Segall, CHt, CHC
IPPF Founder
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An ambition realized despite - and in spite of - pemphigus vulgaris

by Michael Holman

We all look forward during our working careers towards a happy, healthy and enjoyable retirement. There is never a good or convenient time to hear the devastating news that one has been diagnosed with a serious, painful and very troublesome condition such as pemphigus vulgaris, but for me it came on top of other serious health problems. It’s difficult enough coping with the condition itself but coupled with the side effects of all the medication it made the future look bleak, onerous and at times almost hopeless.

For me, a lengthy and very demanding career in the police force resulted in a serious nervous breakdown which seemed to be the obvious start of all my health problems. As a Detective for most of my career, my days were filled with excessive working hours dealing with daily confrontations, very unpleasant people, death and other extremely distressing incidents. This was during years when very little, if any support was available to help police officers cope with the unreasonable mental and physical demands of the job. I always strived to give 100% and although I had seen others similarly affected, I never dreamt that I was a person who could be so seriously affected by the excessive stress imposed on me. Specialists told me that my recovery from such a serious breakdown would be a very lengthy and very difficult path.

I was told I was seriously burnt out and it might take a considerable number of years to restore my mind and body to reasonable health. To then be diagnosed with both Haemachromotosis and PV (both appearing to be triggered as a result of this stress related illness), was -- to say the least -- traumatic, bewildering and completely unhelpful to someone already suffering serious stress related illness. When coupled with the added difficulties that the heavy medication can cause, it would have been easy in the beginning to give up mentally and sit indoors without any focus, ambition or hope whatsoever. But fear not fellow sufferers! It’s still possible to achieve ambitions. I have now been living with this illness for five years and am unfortunately still on high doses of steroids and immunosuppressants with active lesions in my mouth, on my face and occasionally on my body. A relatively new complication is troublesome muscular and joint aches and pains probably resulting from the steroid treatment.

I decided about two years into the illness that I must stay focused and do something to take my mind away from my symptoms as it’s so easy to become com-

Continued on page 12...
I wanted to go in a totally different direction for this article, however life intervened. Life, ain't it grand!!!

I was contacted in September and asked if I would be interested in talking to another patient about her son who was recently diagnosed with PV and was being treated at a local hospital. I jumped at the chance to help anyway I could.

I called Catherine who was such a sweetie over the phone. Concerned because the hospital folks told her that her son would not recover (he was being treated as a burn victim), and they were trying to make him as comfortable as possible. She asked if we could meet at the hospital so I went the next day. Catherine, WOW!!! Not at all what I imagined.

A TINY little lady under five foot tall surrounded by seven other family members. Catherine is 101 years old, her son with the PV is 78. I was floored! Being a "take charge kind of lady," she sat me down in the lobby and asked me about PV, the entire time she held my eyes and my hand. After our "talk" she matter of factly patted my hand and told me I knew more than the "ya-hoos" taking care of her son. Apparently, Catherine is very internet savvy and she and her family researched, made phone calls, etc. to no avail.

With her running shoes and quick pace, I was doing everything I could to keep up with her. She took me to meet Steven, her son with the PV. We went to his room and he had the bandages on like a burn victim, mostly on his head. Steven is bald and the blisters appeared to be all over his scalp, a few in his mouth and upper torso, but that was it! He had about a dozen or so areas that were not so bad, and no infection that I could see. "Cat" as she now insist I call her, went to the charge nurse and wanted the doctor summoned to the room.

I sensed she was a force to be reckoned with and didn't take no for an answer. When Steven could get a word in - after raising his voice to his mother to hush - he said this is the first time he had ever been hospitalized for anything in his entire life. He just wanted to go home, but the doctor said he needed to be treated for his PV and this is all they could do.

Then the hurricane slammed into the room....doctor, nurses, Cat and family began a heated discussion. Oh boy, what did I get myself into?!

Cat calmly took control and kindly asked the doctor to tell me her sons condition. All of it. I had my many encounters with doctors in my life dealing with this disease, and this doctor had such an arrogant attitude that I wanted to smack him - but didn't.

Steven had no other health problems whatsoever. The doctor said he didn't want to put him on steroids because of his age and the side effects. I suggested he contact IPPF and speak to someone who deals with this every day because this was his FIRST patient to have the condition. The doctor and Cat spoke and Steven actually told the doctor to do what I had suggested. "Doc" wasn't happy. I stayed awhile and talked to Steven (poor guy just wanted to go home and finish remodeling his basement) and gave Cat my number to call anytime.

About two and a half weeks later, Bill called me (a great-great grandson) and asked if I was available Saturday afternoon because Cat wanted to see me. Bill said he would pick me up because Cat was not feeling well. This woman still drives? He didn't take no for an answer either (I see a pattern forming here) and he picked me up. We drove, and drove, and drove. An...
Medications can help, and are often necessary. Therapy can teach new ways of coping that will be absolutely necessary to get back in (limited) control and to accept to help move on.

Sometimes techniques can be learned in therapy or from self-help books. I am not a great fan of most self-help books, but new ideas and ways of handling things will be helpful, however they are learned. When new circumstances take people back to old unresolved events or issues that is when psychotherapy will be absolutely necessary.

Fortunately the stigma once attached to the need for psychologists and psychiatrists has changed for most of the population. Asking for help in just understanding why one feels as they do is the first step in taking this course. The support and understanding of others, your support system or lack of one, is never to be underestimated.

So, where are the cheers to come from? How about improvement in the illness’ impact, adjustment to this new life, just being able to sit comfortably or to eat and enjoy food again, feeling more stable, being in partial or full remission, fewer or less harsh drugs? Any or all of the above and so much more are cause for celebration.

What are my recommendations for the holidays and New Year? Take a lot of pictures to help create new memories; try at least one new thing; let the people you love know how much you love and appreciate them in your life; smile more; let go of small disturbing things; say hello to someone you don’t know.

Cheers to all for a happy and healthier New Year. Remember, the IPPF Annual Meeting will be in Detroit in 2011 – May 20-22 – a time to learn from the experts, meet or reunite with others, and to feel connected.

I hope to see you there!

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.

Michael Holman is a retired police officer turned writer after being diagnosed with PV. His work throughout the United Kingdom laid the foundation for his book. You can find out more about him online at mikeholmancrimefiction.co.uk. His book is available at amzn.to/threestepstohell.
hour and twenty minutes later, I'm sitting in front of a beautiful stone home in Gettysburg.

Bill filled me in a bit on Cat and the family. The home sits on a 240 acre orchard, one of the oldest in Gettysburg. Ed and Cat purchased it from her parents. Cat’s husband, Ed, died in 2009 at 104 years old. They were married for 84 years!!!

Ed died because he fell off a ladder head first. He was pulling down something from a shelf in the barn. This family takes everything “matter of factly.” Bill said everyone lives close by if not in the house, somewhere on or around the orchards. I walked into a modernized kitchen that still had an old stone fireplace in it and a “back” staircase that led to the second floor.

Cat showed me around her massive home. Chaos was in the house, and Cat seemed to have eyes and ears everywhere. I asked how she was feeling and she said fine, just pulled a muscle in her leg from her yoga class. Really? I’m in an episode of the twilight zone, right?

We get to the biggest dining room I had ever seen in my life – big enough to hold the family’s five generations. Steven was there and looked so much better. The blisters in his mouth had cleared and his upper torso was well on its way to recovery. He is on 20mg of steroids and his doctor sent him and the family a letter of apology. Steven told me that he is in search of a doctor that is more familiar with the disease and thanked me profusely.

Cat had planned a “Thank you dinner” for me because I helped them. She informed me she was at her wit’s end with getting the doctor to listen to her. I became her weapon of choice. She apologized for using me in that manner, but she said she has always done what needed to be done in life.

Sometimes we feel as if there is nothing we can do for ourselves. However, by just teaching what I know from my own experiences to others put me on top of the world. What an unique ride in life!

Cat sent me home with crates of goodies. No possible way I could finish all of it, so I shared with the local food bank. Steven sent me a beautiful arrangement of flowers, and Cat emails me at least once a week just chit-chatting. This family matriarch taught me a lot in a short amount of time and she has invited me and the entire family to her home for another “get together”.

Adversities in life, if we all would face them like this wonderful young lady, what not but a better view of seeing the beauty in just being!
**REGISTRATION FORM**  
IPPF 2011 Annual Meeting  
May 20-22, 2011 • Detroit, MI

Print Name (as you want it to appear on your name badge)

Organization/Employer Name (Corporate Sponsors Only)

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- PV
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- OCP/MMP
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Register Online: [www.pemphigus.org/2011](http://www.pemphigus.org/2011)

Call our offices: (916) 922-1298 x1003

Contact your Peer Health Coach

Mail this completed form with payment to:  
IPPF AM Registration, 2701 Cottage Way #16, Sacramento CA 95825

Registration cannot be processed without payment. Payment must be in US funds. All cancellations must be received in writing. For cancellations postmarked on or prior to April 29, 2011, we will refund registration costs less $25 administrative fee. Cancellations postmarked between April 29 and May 13, 2011 may be refunded up to 50% of the registration fees. We may be unable to make refunds after May 13, 2011 due to food, beverage and material costs. We will gladly transfer your fees to another person as a scholarship or credit you with a tax-free donation.

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### Annual Meeting Registration Fees Postmarked by:

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- **Early Bird Registration** (postmarked on or before **February 28, 2011**)
- **Registration Fee** (Regular and Onsite) Includes attendance for all three days, materials, food/beverage during scheduled meeting times, two complimentary drinks at Friday's Welcome Reception and Saturday's Mixer. **Subject to change without notice.**
  - Friday Night Reception  $50
  - Saturday  $125
  - Sunday  $75

- **Caregiver Badge** *(may only be purchased with a paid registration)*  $50

- Name to appear on caregiver badge:

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- **Scholarship Donation.** Please help someone else attend this year's meeting.

- **Tax-Free Donation.** Your donation goes to support current and future programs and research.

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* A member of the IPPF will contact all Event Sponsors to coordinate additional details.

- **Check/Money Order made payable in U.S. funds to IPPF**  - VISA  - MasterCard

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