



THE Quarterly

WINTER 2006 • Issue #47

Did You Notice Our New Look?

With the partnering of the IPF and the PPS, we are now the **International Pemphigus & Pemphigoid Foundation (IPPF)**. To honor the change, the new IPPF Board of Directors voted a new logo for the organization. This logo represents the antibody. The antibody is a paramount symbol for pemphigus and pemphigoid.

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Unity, Growth & Progress on Parade

Held in the Saklad Auditorium at the New York University College of Dentistry on September 15-17, the Unity Growth and Progress conference was a treat for attendees. "It was just marvelous, so well organized and really addressed all of our needs and this was the consensus of everyone I spoke to" said **Miriam Weiss** a guest from Brooklyn, New York. "All the different type of treatments were covered and we all appreciated the nutrition and supplements lesson, which we never really addressed (at the local meetings) here in New York."

The conference brought together over 150 patients and caregivers, from as far away as England, for a reception and two days of presentations highlighted by several of the world's foremost researchers and scientists in pemphigus and pemphigoid.

Dr. David Sirois not only secured NYU facilities, but did an outstanding job emceeding both the meeting and the dinner.

The opening event took place on Friday evening with a Welcome Reception. Over 50 people gathered together to meet and greet and take pleasure in beverages and hor's d'ou-

voirs. After the event, several members went to a local eatery to enjoy each others company and local ambience.

The meeting began early the next morning with **Dr. Grant Anhalt**, Johns Hopkins University School of Medicine leading a discussion for new patients on the basics of the immune system, autoimmunity, and how pemphigus/pemphigoid fit into the picture.

After Dr. Anhalt's presentation, Dr. Sirois, **Janet Segall**, Interim Executive Director of the IPF and **Sal Capo**, Executive Director of the PPS, delivered welcome messages to the group hailing the merger between the two groups.

Dr. Russell Hall, Duke University, North Carolina, talked to the group about new and emerging treatments, giving us an update on several clinical trials. At Duke, there are two important trials – one with Rituximab and bullous pemphigoid, one starting with infliximab (Remicade®) and pemphigus vulgaris. He

mentioned several other drugs in this category called biologics that are being considered possible treatments for pemphigus and/or



With typical aplomb, Dr. David Sirois of New York University and IPPF President, acted as Master of Ceremonies over the two days of presentations and also spoke on the oral aspects of pemphigus and pemphigoid in the Sunday morning session.

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Getting Ready for 2007...



Dr. David Sirois,
President,
Board of Directors

Change is good, and 2006 was a good year for the IPPF! Let's start with IPPF – that's not a typographical error. Following talks with Sal Capo, President of the Pemphigus and Pemphigoid Society, we agreed to unify membership and programming between the IPF and the PPS. We celebrated that unification during a spectacular annual meeting and gala in New York City (see the web site for stories and photos from the meeting). Our new official name is **The International Pemphigus & Pemphigoid Foundation**, a more inclusive name representing our constituency. We designed a new logo (the "blue antibody"), are making changes to The Quarterly, and will soon launch a revised and improved web site.

The **2006 Annual Meeting** in New York was a wonderful gathering of new friends and familiar faces representing patients, friends, family, doctors and scientists. A panel of luminaries presented the most contemporary views of disease mechanisms and treatment, as well as management of side effects and an outstanding motivational platform for coping with chronic illness. And we enjoyed a delicious evening of music, food, drink and views at the Water Club. Thanks again to Dr. Bert Konowitz (father of Director Paul Konowitz, M.D.) whose jazz ensemble Spirit provided an evening of wonderful music!

Stay tuned for information on our **September 2007 Annual Meeting in Toronto**. We are planning a brilliant meeting with our Canadian friends in the dazzling city of Toronto, including a fantastic evening culinary and social event!

The IPPF is moving forward along a strategic plan that will improve and expand our impact in patient care and support, education and research. Both our **Board of Directors** and **Medical Advisory Board** are adding new talented members to serve you and the IPPF. We are exploring a novel health program with an industry leader in health management for rare disorders, and hope to deliver a **comprehensive health plan** that will not only optimally treat pemphigus and pemphigoid, but also address global disease prevention, health promotion and wellness. As part of this process, we hope to develop a robust patient registry that will provide desperately-needed information on the natural history of pemphigus and pemphigoid as well as treatment outcomes. This effort will no doubt improve the lives of people living with pemphigus and pemphigoid.

As we close 2006 and welcome 2007, I thank you all for your continued interest in, and support for, the IPPF. We had an excellent year, and we look forward to an even better year in 2007. We are working hard to raise the money necessary to fund our programs. In addition to new and expanded sources of funding, we will continue to ask for your generous contributions **without which the IPPF simply could not exist**. Enjoy this issue of *The Quarterly*, stay tuned for breaking news, and plan to attend upcoming events. Please give generously to the IPPF so we may continue to advocate for care, education and research that improves the lives of people living with pemphigus and pemphigoid. •

Sal: You Will Be Missed

After the IPF merged with PPS, Sal Capo, PPS Executive Director, decided to retire from an active role in the IPPF. Sal has made many contributions to patients living with and suffering from pemphigus and pemphigoid. When the IPF was still a young or-

ganization, Sal created not only our logo, but our motto, "a common hope, an uncommon bond". He made the IPF newsletter look professional and brought his writing talents to the forefront on many occasions. Sal's need to gain knowledge, search out and report on everything pemphigus and pemphigoid as well as additional relevant information, improved the lives of patients and caregivers. He always gave 100% to everything he did. He definitely will be missed. •

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The International Pemphigus & Pemphigoid Foundation is a 501(c)(3) nonprofit organization.

Our goals are to increase awareness of pemphigus and pemphigoid among the public and the medical community; to provide information and emotional support to pemphigus or pemphigoid patients and caregivers; to provide referrals to specialists; and to support research into advanced treatments and a cure.

Founded in 1994.

The *Quarterly* is published: Spring, Summer, Fall and Winter.

The *Quarterly* is provided free of charge to our donors as a thank you for their support.

The material presented in our journal is not intended as medical advice. Readers are urged to consult their physicians before making any changes in their health regimen.

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We Must Work Together!



Janet Segall,
Interim Executive
Director

Along with the most successful annual meeting and dinner event ever, on September 17, 2006, the IPF and the PPS merged as one organization – the **International Pemphigus & Pemphigoid Foundation (IPPF)**. Bringing patients into one big family can only be in the best interest of all. I am so thankful for the great leadership we received from **Dr. David Sirois**, and all the people who worked collectively to make this event the winner it was.

At the end of the meeting on Sunday, after our patient panel, and caregiver meeting, we held a focus group on how patient manage their disease. One thing became very clear to me. It is so extremely important that all of us living with and suffering from pemphigus or pemphigoid must work together. What do I mean? We have all talked about trying to get the right media attention. "If only we could get our disease out there, things might be different." I came to the conclusion that we need to re-focus our energies. I was one of those people who believed "if only..." but I realized that media attention for pemphigus or pemphigoid would do nothing but give us less than our 15 minutes of fame. There are so many social and medical issues out there. How could we ever compete for the appropriate attention? And, even if we got that attention, how long would it last?

There is only one answer – and that answer is that **we all need to work together to help ourselves**. Be proactive. Many of us are very busy in our lives and feel that there is not one minute more they can do. But, I say, there is always one thing more someone could do. Be a part of our **Heart 2 Heart** list and take a call from someone in your area from time to time who has just been diagnosed and needs someone like you to talk too. Write a letter to your Congresspersons both in the Senate and the House and insists that, as your representative, they use their clout to make sure a patient gets the proper healthcare, or there is more research dollars for the NIH. If you have a little more time, become a support group leader or share the role with someone else in your area so no one with pemphigus or pemphigoid has to feel alone. You could write an article for the newsletter, or host a small fundraising event (a bake sale, or a car wash). You could make sure your doctor has Foundation information for new patients. Or make sure the doctors you see who aren't familiar with pemphigus, like your internist or your gastroenterologist, at least have some information in their office on pemphigus/pemphigoid in case they really need it.

We can only depend on ourselves and the people who care about us to work toward a better outcome for all of us.

Whether we get one story or 10 stories in the media or online, it will never accomplish what all of us working together can do. ●

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pemphigoid including etanercept (Enbrel®) which is also in clinical trial for PV at Stanford in California, and in Boston.

As emerging therapies are being tested, there are some scientists looking into the core science of autoimmunity specifically targeted at pemphigus.

Dr. Animesh Sinha, University of Michigan, East Lansing, discussed the importance of basic research in development of treatments. He talked about his research on T-cells and how they contribute to the disease mechanism.

Dr. Sinha was able to set up a blood draw at the Dental School asking meeting participants to give several vials to help with his research. Appointments for blood draws were set throughout the day on Saturday, and on Sunday morning. Every time slot for blood draw was filled. Participants were eager to help Dr. Sinha with his research. We applaud the willingness of everyone to be a part of this project.

"I was extremely impressed with the professionalism of the conference."

Dr. Anhalt again took the stage and gave us a very good picture of steroid use, remission, and the growing use of Rituximab as a good viable treatment for both pemphigus and pemphigoid. He also discussed the difficulty in getting a drug approved for use in these diseases because of their rarity.

After the break, pharmacist **Ashar Hassan, R.Ph, MBA** and a staff member of the home-healthcare company Crescent Healthcare, gave us an overview of our drugs, their side effects and common drug interactions. Then **Dr. Victoria Werth**, Dept. of Dermatology,

University of Pennsylvania, Philadelphia and talked extensively about steroids: how doses are administered, their side effects, and how to cope with steroids more effectively.

To round out the morning, our experts

all came on stage to answer questions.

After lunch, the afternoon session opened with **Joanne Klauke-LaBelle**, a motivational speaker, CEO of **Harmony for Youth** (a non-profit organization in Canada bringing music to youth), and

Below - Caregivers attend a Caregiver's Workshop.



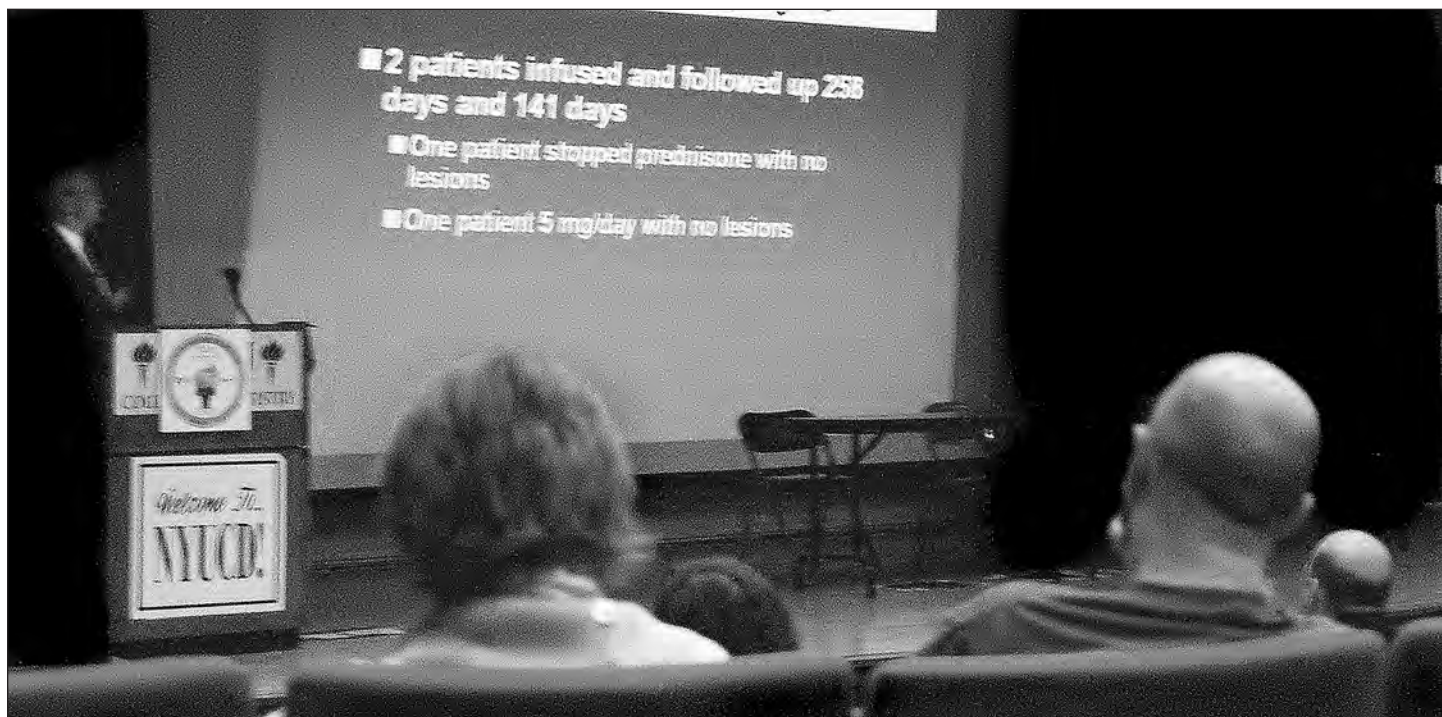
a pemphigus patient. Joanne talked about how she learned about her disease, found ways to keep her spirits up, and stay positive in spite of several debilitating health issues.

Nutrition took center stage next.

Diane Rigassio Radler, Ph.D., a registered dietician on the staff of UMDNJ's School of Health in New Jersey. Dr. Radler explained the impact of active oral lesions on nutrition. She discussed the food pyramid, tips on food preparation and best ways to consume food with mouth sores present. She also talked about foods to avoid and the research and case reports that suggest certain foods might trigger an outbreak.

Bringing up a very sensitive subject, but important one, **Dr. Razzaque Ahmed**, New England Baptist Hospital,

continued on page 5...



In the Saklad Auditorium on Saturday, Duke's Dr. Russell Hall explains the finer points of a study in which Rituximab was used to treat bullous pemphigoid patients.

...continued from ANNUAL MEETING, page 4

Boston, gave a presentation on the subject of genital and anal disease. Many patients deal with this issue which can be a difficult one for people to speak about. He talked to the group about the difficulties in caring for these kinds of lesions and gave some very helpful hints.

Rounding out the day's presentation, **Diane Maydeck-Youngberk, RN, MSN**, a clinical nurse specialist in wound care at NYU discussed the different kinds, of blisters, and the best way to patients to manage their wounds and pain. She discussed the different types of bandages available and which ones would be the best for use by patients with pemphigus/pemphigoid.

The day's event closed with another question and answer session. Joining the session was **Dr. Neil Korman**, Case Western Reserve University, Cleveland, OH, and **Dr. Jean-Claude Bystryn**, New York University, NY.

Sunday's meeting was less formal with Dr. Sirois leading us off with a discussion on Oral Health and Pemphigus/Pemphigoid. Dr. Sirois feels that the dental community needs to be better informed about these diseases because disease will usually appear first in the mucous membranes of the mouth. Often with people who show mouth lesions before skin lesions, diagnoses can take longer.

He described the way the lesions look orally, and that it is often difficult to tell one from another, but he explained that there are clues. He talked about how important it is to treat mouth lesions as well as skin lesions. Open mouth sore can lead to loss of teeth.

The meeting ended with our patient panel and an open discussion on our thoughts and feelings living with and suffering from pemphigus and pemphigoid.

Interim Executive Director and show organizer, **Janet Segall** was pleased. "I was extremely impressed with the professionalism of the conference. We made an effort to gear the lectures toward topics which would

Right - Volunteer blood donors listen to the procedures at Dr. Sinha's information table. Fifty people donated blood for Sinha's research project, which involves the studying binding sites of antibody molecules.



Below - IPPF Director Marcia Pepper of Florida, looks over the healthy treats served at the Saturday breakfast buffet prior to the presentations as caterer Tina Wayne of the Bagel Chateau looks on. She also provided a tasty box lunches at the midday break.



be more informative and helpful for patients.

"We added an additional Q&A sections that provided participants with more constructive and relevant answers for better understanding of their disease. I commend the speakers for their efforts as scientists and physicians toward making their presentations more patient friendly. I think everyone walked away with something new." All in all, the meeting was a tremendous success. We want to thank all the participants including our Sponsors, presenters, volunteers, and the audience for making this the best meeting ever. We look forward to seeing you at next year's Annual Meeting in **Toronto, Ontario, Canada.** ●



Above - Dr. Grant Anhalt delivers the basics on pemphigus & pemphigoid in the first lecture of the day.

Annual Meeting's Gala Dinner Serves Up More than Great Food

After a serious day of information, the event moved to one of New York's finest restaurants, **the Water Club**, with its spectacular views of the New York shore line and cityscape. Attended by over 170 people, the evening began with cocktails and hors' d'oeuvres and continued with a wonderful dinner and wine. Entertainment was donated by *Spirit*, the renowned improvisational arts ensemble from New York's Columbia University. By 'coincidence,' the band is lead by **Dr. Bert Konowitz**, father of Foundation Director, **Dr. Paul Konowitz**. We want to thank both Drs. Konowitz, and *Spirit* for their wonderful performance.

During dinner, **Dr. Dave Sirois**, as emcee, gave away more door prizes; and raffle winners were picked. He thanked the volunteers, and staff, and introduced the evening speakers. Joanne Klauke-LaBelle spoke

openly about living with pemphigus, and keeping positive in the face of life's difficulties. **Janet Segall**, Interim Executive Director of the IPF, talked passionately about why she started the IPF and thanked her family for helping and supporting her through those first difficult years. Janet then presented several awards.

Our special guest, for the evening was **Dr. Stephen I. Katz**, Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Dr. Katz received our special *Excellence in Leadership Award* for all his contributions not only in pemphigus but in skin disease research and autoimmunity. Janet met Dr. Katz for the first time in 1998 when the IPF, as a new organization, joined the Coalition of Skin Diseases. Throughout the years, Dr. Katz gave Janet encouragement to continue her efforts to keep the IPF viable. With Dr.

Katz' support, the IPF was able to hold two scientific conferences at the NIH, bringing together researchers and scientists to discuss all aspects of pemphigus. Dr. Katz graciously accepted our award, and talked about his long history and commitment to NIAM's programs. We are so grateful to Dr. Katz for his continued efforts on behalf



Dr. Paul Konowitz introduces his father Dr. Bert Konowitz, of Columbia University and leader of the group *Spirit*.

of all people living with skin diseases.

Although he was unable to attend this year's conference, the Foundation awarded the *Volunteer of the Year Award* to **Alan Papert**, Boston's support group leader. Alan is also a member of our online e-mail discussion group. Since his diagnosis, Alan has participated in all the previous annual meetings, as well as our Capitol Hill Day. He has shown leadership and commitment to helping patients with pemphigus whenever he can. With all that Alan has done and continues to do, we just couldn't wait until next year to honor him.

Matt Koenig, leader of the NY Support Group, received the *Outstanding Service Award*. In 1994, Matt received the Volunteer of the Year Award, but with his contributions over many years both to the Foundation and to patients not only in NY, but everywhere, we felt that Matt needed something more. Matt was the first volunteer for Peptimmune's clinical trial. He stood out as a role model and encouraged others to step up. He has volunteered his time at our annual meetings and as a confidant for many of us. Thanks Matt for all you have accomplished. ●



Special Guest Speaker, Dr. Stephen Katz Director of NIAMS, poses with Janet Segall after receiving the Leadership Award at Saturday night's gala dinner banquet.



Dutch Pemphigus and Pemphigoid Patients Flock to Get in the Picture

by *Hermein Konnings*
Netwerk Nederland voor Pemphigus & Pemfigoid

For the first time in the Netherlands, on September 20, 2006, a conference was held by the Dermatology Department of the **Groningen University Hospital**, the Netherlands, and the **Netwerk Nederland voor Pemphigus & Pemfigoid**. Some 105 patients and their partners or caretakers travelled to Groningen from all over the country and Belgium.

Never before in the Netherlands could this many patients meet each other and discuss their individual ways of coping with their diseases. One of the member said "My, did I learn a lot today!" Another commented, "I don't know how it is possible, but I had a party today!"

By means of three presentations by **Marcel Jonkman**, Professor and chair of Dermatology at Groningen, and one of his assistants, **Annemarie van Houten**, M.Sc., displayed in plain Dutch language the various blistering skin diseases, their Groningen treatment and

the recent medical-scientific developments. A participant of the Network, **Mrs. Truus Borsje**, a patient herself, presented her way of coping with all her physical and mental troubles as a result of her BP, illustrated with her often self-improvised tools for handling her blisters and other sore places. Her concluding words: "Doctors, be quicker with your diagnosis; patients, do enjoy your life!"

Finally, more than 70 various patient-questions were dealt with by a panel. This resulted in very animated plenary discussions, also about some very intimate topics.

During breaks, visitors could inform themselves about wound-care, dressing-materials and oral care. An unbelievable instructive, animated and healthy day! •

Netwerk Nederland voor Pemphigus & Pemfigoid



Top left, 105 guests attended the first conference in the Netherlands. Above, Dr. Marcel Jonkman addresses patients. Below, patient Truus Borsje discusses her personal solutions to BP. Bottom, Hermein Konnings, conference organizer, offers educational materials to conference guests.



Things Happen for a Reason

by Amanda Staso, Age 14

Throughout everyone's lives important events take place that help shape the kind of person they are today or will become. Some events may be [painful] to talk about while others may bring joy and happiness.



Amanda Staso

October of last year my mouth started to develop what I thought were normal mouth ulcers. I dealt with them and assumed they'd eventually go away. Once several weeks had passed and my mouth still had not cleared up, I decided to tell my mom. She told me give it a little more time and see if they heal. My mouth got progressively worse. My mom made a doctor's appointment and we went. The doctor suggested oral rinses and gels. I took their advice but nothing seemed to help. One evening I told my mom to stop calling the doctors because I've come to terms with the fact I'm going to have these ulcers for the rest of my life. At the time, she of course thought I was being a dramatic teenager and told me that was ridiculous. Little did we both know, I was right.

Christmas was coming and I still was not well. The ulcers were now becoming so severe I couldn't eat or drink much of anything. I was losing a lot of weight and my skin was getting a grayish tone. Not only did I have not have any energy at all, but I was missing vast amounts of school. Deep down, I knew something wasn't right. Christmas passed and New Year's came. Every morning I would wake up with a new blister in my mouth. One of the few days I actually went to school, I got called down to the office. My mom had called to tell me I was going to be admitted to the hospital and she would pick me up soon. By that time I was spitting up blood and I was terribly desperate to get better.

Once my mom and I arrived at the hospital and got settled in my room, the nurses gave me an IV with fluid to rehydrate me and we met with the doctor. He said I would probably be in

the hospital for a few days. I was terrified and extremely upset because I felt as if I were trapped and helpless. Two days later I got several tests done and was able to go home. After I got home my friends called and told me to go to a local restaurant so they could see me. At the time it seemed like a good idea but looking back I realize I should have never gone.

The whole time I was there I felt as if my friends had forgotten about me since I hadn't been myself for so long. I remember feeling terribly betrayed. I went home and for the next week I didn't get out of bed. I was mentally, physically, and emotionally exhausted, and I had no idea what was yet to come.

Toward the middle of February I was diagnosed with pemphigus. The doctors at Children's Hospital had never seen a child with this disease. My family began to panic because the doctors didn't know how to treat me. After researching, my mom finally found a doctor at the Johns Hopkins Hospital. There, Dr. Anhalt checked out my mouth and clarified that it was indeed pemphigus vulgaris, the type that manifests mainly in mucous membranes and rarely on the skin.

I was immediately put on prednisone. The doctors informed me of the side effects of this particular medication but I never actually thought they would happen to me.

Three months passed and the only side effect I really noticed was an increase of appetite. I figured I could live with that until I was off the medication. Plus, since my mouth was feeling better and I could actually eat again, having an appetite wasn't all that bad.

Around (3 months) later the terrible side effects kicked in. Mood swings, weight gain, swollen face, stomach pains, and migraines were just a few. I felt like a monster, and as if no one wanted to be around me.

I was losing friends and fighting over pointless things. I just wanted everything to end. I started to get angry because of how I looked and felt and knew there was nothing I could do. I kept asking myself, "What did I do to deserve this?" The doctors told me over and over that as my medication dosage

decreased the side effects would as well. I was feeling so miserable at the time I didn't believe them.

As time went on, I felt as if I was on my way to remission and getting off the terrible steroid. This summer I got down to 10 milligrams of medicine every other day. The weight started to come off, my face was getting back to normal, and I was starting to feel like myself again. Unfortunately, toward the end of this summer I got a virus which turned into a flare up of my disease. I made it to the first two days of school then was out the next 2 weeks. My throat was covered with ulcers. Food and drink were completely out of the question.

We called the doctors and they told me to go back up to 30 milligrams of the prednisone. I am now still at 30 milligrams and I'm feeling much better than I was in the beginning of the year. This whole experience truly has changed who I am as person. I realized that I'm not going to let myself be an average, catty, mean teenage girl. Being sick and going through a stage where I felt terrible about myself and my appearance made me stop judging people and look deeper than just the outside.

Going to the hospital so many times also opened my eyes and made me realize things could be a lot worse. Seeing all those kids who were dying made me rethink pitying myself and having anyone else pity me, because when I thought about it, I was still alive and for the most part healthy.

I've learned to base my life on the saying, "Everything happens for a reason." Getting sick might not have been in my life plans, but it has made me a more mature, compassionate, understanding, and stronger person. I am able to brush off the little girl fights everyone gets into at my age because I realize there are things so much more important.

Doctor appointments have become a way of life and I've learned to deal with it. There's no sense in fighting what you can't change. I'm just grateful there are such good doctors around that can take care of me.

One thing I promise myself is that, no matter what happens, I will live life to the fullest and not dwell on the negative, but try to be as positive as I possibly can be. ●

PEM Friends (UK) has BIG Plans for 2007!

The IPPF is proud to announce two fantastic opportunities for people living in and near the United Kingdom. **PEM Friends (UK)** Support Group Leader **Carolyn Blain** has continued to be a driving force in warming and informing patients and caregivers and 2007 is no exception!

On the **26 February 2007** they will host a lunch in London. Anyone interested in joining would be most welcome. For more information, please contact Carolyn.

Over the weekend of **29 June 2007**, PEM Friends (UK) will be having its third

'away weekend'. Everyone is welcome and those participating are guests of Carolyn and Raymond Blain in one of their spacious self-catering holiday homes, which is just by their own house. Lots of fun, camaraderie, the opportunity of talking about PV, PF, etc. with people who understand - and the chance to make new friends. Please contact Carolyn for more information.

PEM Friends (UK)
Carolyn Blain
+44 161 343 7100 or email
carolynblain77@hotmail.com

MI Gathering Shows Interest

A small group of folks gathered in Lansing, Michigan on November 11, 2006 in hopes of forming a local support group.

Julie McKeever organized the informal gathering for patients hoping to form a Michigan/Indiana Support Group. While only a few people attended, there are others who expressed interest. If you live nearby or would like more information, please contact Julie.

Julie McKeever
616-836-9076 or email
sdjmckeever@msn.com

If you are interested in starting a local support group in your area call the IPPF at **(916) 922-1298** or email Janet at jsegall@pemphigus.org. •

IPPF LOCAL SUPPORT GROUPS

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cell 864-386-1620, bubba2coggins@juno.com
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- Texas (Houston)** - Looking for a Group Leader
- England/UK -**
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Advice for the "Pill Weary"

by Terry Wolinsky McDonald, PhD
Licensed Psychologist

Ah, the dilemmas of chronic illness. Unlike cancer, heart disease, stroke, or other acute and life-threatening conditions, chronic illnesses like pemphigus or pemphigoid do not mean using very



Dr. McDonald

aggressive treatments and then having the disease removed. Nor do the diseases have name recognition. It is like a never ending story but not like a storybook. Previously published articles have addressed "coming to terms with your illness" and "compliance" issues, which are all relative now.

This article was prompted by patients who want to be permanently off potentially harmful medications. Don't we all? In an ideal world we would be, but who says this is an ideal world? I am not happy about my situation, but I am grateful to be alive after almost 6 years of PV.

The term 'chronic' means just that; it's not going to just go away. We all dream of remission, of getting off medications, which may or may not happen. At the Unity Conference in NYC (September 2006) I kept hearing Mission Remission! For many of us remission may not happen, but that doesn't stop us from wishing and working for it and planning/ hoping for this outcome.

When one of my own patients recently had difficulties with her insurance company (a one month lapse in coverage), she tried to explain that she had two serious chronic illnesses for which she needed out patient hospitalizations and infusions. Finally, she just asked them "what part of chronic they didn't understand." She did get her coverage reinstated, and she refused to back down, taking back control over her life and her conditions—at least

partially.

She insisted they 'google' chronic on the internet if they didn't understand the dictionary definition. This was an empowering experience for her. It may also have saved her life. Many patients have issues with medications – sometimes because of the idea of pills and more pills, ointments, compounds; with side effects and money issues.

Ultimately unless we are taking our medications as prescribed by our doctors, we are being noncompliant. If we are noncompliant with our treatment as prescribed by the doctors caring for us, we are not working in our best interest and are toying with our conditions and futures.

Of course, if it gives us a feeling of being in control the rational reasons for compliance seem to fade. Education is empowering; noncompliance is simply not acceptable. Doctors can, and often do, 'fire' patients who are not compliant. If the patient has been noncompliant with treatment, this is not considered "abandoning" the patient. If there isn't confidence and trust, it is probably in everyone's best interest to part ways.

Many patients taking medications and receiving therapeutic help for psychological issues, who begin to feel better, unilaterally decide to stop their psychotropic medications without telling anyone. Because of the "half life" (the beneficial effects of these drugs stay with people for a while after they have been terminated) of most of these medicines the patient often feels okay for a couple of weeks, but then goes back to baseline and only then realizes that the pills were actually helping them. For most people this becomes a wakeup call.

On a personal note, I stopped counting my own pills years ago, although I do carry around a list of all my prescription, over the counter and vitamin pills plus any other compound formulas. I also wear a medic alert bracelet and make sure that all information is up

to date. When I see a new doctor I ask their office to make a copy of my list for my chart; this saves me time completing all this new patient information. It also empowers me to have this part of my journey under some control.

Even supplements need to be reported because of various drug interactions. Your pharmacist can at times be your best friend. Be careful, and make sure the lists are complete. Your doctors will welcome your lists and proactive involvement in your life. Having a good working relationship with your doctors helps your journey on many levels. Make sure to keep your lists of medications up to date.

On a recent Caribbean cruise I skipped the required demonstration for life boats; I know this was not right, but all my luggage hadn't gotten to the room, and I wanted to make sure I had all my medications prior to leaving port. I remember thinking

"How will I ever be able to carry all my meds with me on a life boat?" I guess I could bring only some of them, but we would need to be rescued quickly! I chose to conjure up how to carry them with me at all times. With these illnesses we don't have the luxury of taking things for granted. I prefer to not think "gloom and doom" but rather to be rationally optimistic. Being proactive in my treatment is critical, as is being compliant.

Okay, so how do we ever get used to it? First, remember "Whatever happens, don't get upset. Think about what could have happened that could be worse and be grateful that didn't happen." (That was one of my late grandmother's favorite expressions.) There are actually many ways to view things.

A favorite cartoon I used to post in my office had four parts to it. Each part contained a table with a glass partially filled with water. The first guy walks by and says, "Oh, the glass is half full." The second guy walks by and says, "Oh, the glass is half empty." The third guy walks by and says, "Oh, there's a glass with some water in it." And, the fourth guy

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...continued from *PILL WEARY*, page 10

walks by and says, "Where's the cheeseburger?" We always have choices, even when we do not appear to have them. Sometimes we do have to think outside the box, but keeping our doctors in the loop will always work to our advantage.

The point is there are different ways of looking at the same situation. Humor does help, as does deflecting some negative things. **Meredith Vierra** (who has recently replaced **Katie Couric** on the Today Show), married her husband Richard even knowing he had MS and that there was no way to predict his chronic and progressive illness.

When still able to commute by subway to his job as a TV producer, Meredith was questioned by a neighbor "concerned" about Richard's gait. The neighbor was relieved to hear he had MS since she had thought he might have a drinking problem!

Then, as he describes in his book, he was blindsided by colon cancer. The book does make interesting reading. It shows the differences between chronic versus acute illness. With chronic illness every day is a challenge, but some days are less challenging than others. People are often at a loss as to what to say to us. Their favorite expression seems to be "You're looking well; you must be getting better." Yea, right—if they only knew, but they don't and probably can't understand.

Then again, if you believe them and are feeling better, this may reinforce your own feelings about not wanting to take all those prescribed medications, or you may want to cut back on the dosage without telling anyone.

It can be so frustrating to deal with people with good intentions who don't understand. We have choices with these people. We can either try to explain our situation until we are

blue in the face (kind of like trying to convince a brick wall) and use up our positive energy; we can say "thank you" and not be overly sensitive. We can tell them "it's the make up, the haircut" or whatever.

We can have note cards or papers already made up with explanations, and even pictures of our diseases, to save us from explanations

if we believe we need to explain. The options are endless.

Whatever you decide to do, make an informed choice; do what will be most positive for you and where you are both physically and psychologically.

Remember, people with other diseases like thyroid problems, Type 1 diabetes, heart and lupus patients are also taking medications daily. Keep taking your medications unless your doctors make changes, but you can take charge of your life with meditation, exercise, and healthy life choices. This way the pills are not running your life; they are simply part of your life and journey with this rare and potentially deadly illness.

In other words, do not allow yourself to be defined by your illness and medications; be the best you that you can be, with the disease, pills and treatments as just part of your identity. It is up to you how to best live your life, but if you are part of the team with your doctors, caregivers, support group, etc

Be a co-pilot and not just a passenger, you are playing an active role in the life you have been given. You are not just a statistic: You have the ability to empower yourself. This is not a passive role.

As a psychologist I believe strongly in the mental health aspects associated with serious chronic illnesses. I will continue to recommend a psychological evaluation at least annually, like other health-related issues.

So, you can choose to be sick and tired of being sick and tired, or you can be grateful to be alive and make informed

choices about your life. You can make informed choices about how to live your life to your (newly defined) potential.

One anonymous quote I keep around my office is: "**Happiness about my living situation is something I can decide ahead of time.**"

Whether I like my home or office doesn't depend on the paint colors or how the furniture is arranged. It is how I arrange my mind. And, we all have the ability to rearrange our minds. This is empowering.

Enjoy the fall, as nature shows us the seasons. When those beautiful leaves fall from the trees, we know that those trees will be barren during the winter, except for snow and some beautiful winter wonderlands.

We also know that new leaves will appear miraculously on those trees again in the spring and summer. If you live in certain warmer climates you may be lucky enough to have those leaves, flowers and fruit all year long, but renewal is universal.

As always, questions, comments, and ideas for future columns are always welcome, Tmcdii2@msn.com. ●

"...do what will be most positive for you and where you are both physically and psychologically."

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The IPPF offers a shopper's affiliation page on our site!

Merchants such as **Amazon.com**, **WalMart**, **GiftBaskets.com**, **Easy Click Travel** and others! We are excited to offer this service to you - services we all use, only now the IPPF can receive a portion of your purchase towards our fundraising efforts.

Traveling with Medications?



Traveling adds layer of concern for people taking medications, but the hassle can be reduced, if one knows how.

Security rules

Flying? First, check with your local airport about current national security rules and procedures. Then, check again the day before you leave in case anything has changed. You should also check about the rules at your destination. Drugs that are sold over-the-counter here, may be by prescription only there. If you are crossing time zones, ask your doctor to see if you need to make any adjustments to your schedule.

The drugs

If possible, put your medications in your check-on bag so they won't get lost. You may also need some of your medications while in transit. Keep the pills in the originally labeled container so anyone inspecting will be able to identify them. Take extra in case you lose or spill some, or in case you are detained away from home. Placing drugs in an unpressurized hold of an airplane may affect some medications. You may need an insulated bag for medications in some climates.

Paperwork

Take your prescriptions with you, but don't put them in the same bag as your meds! You don't want to lose both

your pills and the prescription. Remember that even with the proper prescription, getting drugs from an unfamiliar pharmacy may be difficult, especially if you are out of the country. Make sure you have your insurance card and the contact information for all your doctors and medical insurance

provider. Know in advance where you can get medical help at your destination.

Contact info

It is always a good idea to keep a current list of all the medicines and supplements you take by brand or

generic name, the dosages and the reason you are taking them. If you have allergies, list them. Some experts suggest you carry a letter from your health care provider stating the drugs you take, the dose and why you need the medication. This is especially important if you carry narcotics or syringes. Since you may not be able to speak for yourself, Medi-Alert® jewelry might be a wise idea. You can reach Medic-Alert® at www.medicalert.com or 888-633-4298.

Local transport options

Nationally over 6000 local transportation options services are available to help seniors and the disabled get around town. They include dial-a-ride, bus tokens or transit passes, taxi vouchers and mileage reimbursement to volunteers or program participants. The American Association for Retired Persons has a state-by-state list of these options available online at www.aarp.org/bulletin/yourlife/state_by_state_transportation.html •

Flu Shots Do Not Trigger BP

World wide research review

Occasionally the *Quarterly* reviews and summarizes some of the recently published research articles of interest to pemphigus and pemphigoid patients, as well as physicians treating these diseases.

Pemphigoid

A study at the Complejo Hospitalario de Pontevedra, Spain looked into influenza vaccinations as a possible trigger for bullous pemphigoid (BP). To detect a difference in the rate of admissions to hospitals for BP during population influenza vaccination program, which are mainly targeted at individuals aged 65 years or older, studies started in the last week of September and last for 2 months. A study in Galicia, north-west Spain (1997-2005), was restricted to people aged 65 years or older.

There were 29 admissions registered during 'vaccination periods' (i.e. approximately 10 weeks per year, including the period of vaccination and two further weeks), and 158 during nonvaccination periods (the rest of the year). The incidence rate ratio of admissions for BP in vaccination vs. nonvaccination periods was 0.85. Researchers reported, "Our data do not support the hypothesis of influenza vaccination being an important trigger for severe BP." *Br J Dermatol.* 2006 Oct;155(4):820-3.

Pemphigus

Scientists at the University of Lubeck, Germany are attempting to formulate a treatment for pemphigus vulgaris, (PV) using protein A immunoadsorption (PAIA) to be an effective adjuvant treatment for induction of remission in severe pemphigus. Nine

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Heart ♡ Heart

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patients with PV were treated with a modified protocol characterized by a combination of PAIA with a higher initial dose of systemic methylprednisolone (2 mg/kg).

In addition, azathioprine or mycophenolate mofetil was administered as a steroid-sparing agent. In all nine patients treated with this regimen, we observed a sharp decline of circulating autoantibody levels and dramatic improvement of cutaneous and mucosal lesions within 4 weeks. The patients remained free of clinical disease for up to 26 months after PAIA treatment was discontinued. *Clin Exp Dermatol.* 2006 Nov;31(6):768-74.

A report on ocular involvement in 11 patients with PV was performed by the Massachusetts Eye and Ear Infirmary of Harvard Medical School, Boston, Massachusetts. Scientists reviewed 11 biopsy-proven patients with PV treated during the period between 1990 and 2003. Ocular disease was preceded by involvement of the skin, other [mucous membranes] in all patients.

Ocular involvement was limited to the conjunctivae, the eyelids, or both. PV did not affect the visual acuity of any of the patients. Recurrence of ocular disease occurred in 3 patients; recurrence at nonocular mucosae occurred in 4 patients. No sequelae [A disease triggered by the original disease.], were observed during detailed follow-up. Ocular pemphigus improved with systemic therapy. The mean remission period was 32 months. Ocular involvement in PV is rare and involvement is limited to the conjunctiva, the eyelids, or both. PV does not appear to affect visual acuity. *J Am Acad Dermatol.* 2005 Oct;53(4):585-90.

Remission Prediction?

Researchers at the University of Medical Sciences at Tehran, Iran studied 57 PV patients to determine if immunofluorescent tests have any value in predicting remission. All patients were in clinical remission for at least 3 months while taking prednisolone 5-7.5 mg/day. Direct immunofluores-

cence study had been performed in all patients after a period of at least 3 months in clinical remission. Treatment had been discontinued in all patients with negative results of direct immunofluorescence. Twenty-four patients (42%) had negative and 33 patients (58%) had positive results of direct immunofluorescence. Eleven patients (46%) with negative results of direct immunofluorescence relapsed within the first year of the follow-up period. Nine patients with negative direct immunofluorescence had a history of more than 6 months of clinical remission before direct immunofluorescence study. Among them, two patients (22%) relapsed. None of four patients with history of more than 12 months of clinical remission before a negative direct immunofluorescence study relapsed. They conclude that negative direct immunofluorescence is an indicator of immunological remission in PV patients after 6-12 months in clinical remission. *Int J Dermatol.* 2006 Nov;45(11):1308-11.

Both pemphigus and pemphigoid

From Aristotle University of Thessaloniki, Greece comes a report that although there is much literature on the detection of pemphigus and pemphigoid autoantibodies by enzyme-linked immunosorbent assay (ELISA) in serum, nothing is known about their presence in saliva. The aim of this study was to evaluate the salivary levels of these autoantibodies in pemphigus and pemphigoid patients. Autoantibodies against desmoglein3, desmoglein1, [pemphigus] and BP180 [pemphigoid] were assayed, by ELISA, in serum and saliva samples of patients and healthy controls. The titres of autoantibodies against Dsg1/3 found in both serum and saliva of pemphigus patients showed a statistically significant correlation, suggesting that saliva may be a useful biological material for diagnostic purposes, in monitoring disease activity, as well as for the early detection of relapses. *Eur J Oral Sci.* 2006 Oct;114(5):374-80. •

Thank You to our 2006 Meeting Supporters

We cannot say enough about the help our volunteers provided to make the meeting the success it was. Help and support was provided by members of the IPF & PPS Board and the NY Support Group members. A special thanks goes to the amazing contributions of **Patricia Montalbano**, Dr. Sirois' colleague at NYU, who was the driving force behind the scenes.

Rebecca Albrecht put together a wonderful poster display on the history of pemphigus. She also secured two tickets to the Broadway show *Avenue Q*, which was raffled during the evening. Rebecca was also able to provide door prizes and raffle prizes of Yoga products through **Yamuna** products which were distributed both at the meeting and dinner.

Tina Wayne generously through her catering business, *Tina Wayne Catering/Bagel Chateau*, provided a wonderful breakfast of bagels, and smoked salmon to all participants.

Ken Gin donated dinner for two at his uptown French Bistro, *Alouette*.

Samples were provided for us from **Walgreens®** thanks to **Nicole Baron**. Samples also came from **Johnson & Johnson®**, **MPL** dental products, **Prompt Care, Inc.**, and **Talecris Biotherapeutics**.

To help with fundraising, **Rachel Youngren** offered the Foundation 30% of her sales through **The Pampered Chef®**.

A big thank you goes out to the **Domb and Hershberg families** for giving us a big discount on hotel rooms at the Lucerne and Belvedere hotels. •

Dual Treatment Shows Promise

by *Sal Capo*

Could this be the beginning of the end of prednisone as a treatment for pemphigus and pemphigoid? Do we dare to hope?

The October issue of the *New England Journal of Medicine* reports the startling success of a novel treatment for pemphigus used by doctors at the Dana-Farber Cancer Institute and Harvard Medical School. Advanced by **Dr. A. Razzaque Ahmed** of Harvard Medical School, the new protocol combines two treatments usually used separately into one. The two treatments are rituximab (brand name, Rituxan®), a drug used to treat Non-Hodgkin's Lymphoma; and intravenous immunoglobulin, (IVIg), which has been used for years to treat pemphigus and pemphigoid.

Dr. Marshall Posner, a coauthor and director of head and neck oncology at the Dana-Farber and Harvard Medical Center called this treatment

"a homerun." Dr. Ahmed said, "If used correctly and cautiously, it can produce long term remissions."

Eleven patients participated in this first-of-its-kind study. These patients, with 30% of their body affected or 3 or more mucosal sites, or both, for over six years, had tried corticosteroids and IVIG without success.

The new protocol gives patients 2 cycles of rituximab weekly for 3 weeks. On the following week IVIG is infused. Then, for the following 4 months, both products are given. Nine patients

achieved remission in an average of 32 months and the remaining 2 inside of 37 months. Two patients relapsed but rituximab alone returned them to remission. One patient, **Peter Reich**, Director of Special Projects at Boston University's School of Medicine had been in a coma for 9 weeks, but with this treatment, he was able to return to work full time.

Unlike patients who receive rituximab alone there were "virtually" no serious side effects seen in the 11 test subjects. **Dr. John Stanley** of the University of Pennsylvania, and a member of the IPF Medical Advisory Board, wrote in review of the study, that he believes this combination therapy is "likely" to work in less severe cases of pemphigus.

The 'catch' is that this treatment is very expensive. IVIG treatments alone are in the \$10,000 per infusion range, and insurance companies are likely to resist paying for this protocol, which is not yet approved by the Federal Drug Administration.

Stanley says that due to the cost, this protocol may not become available to doctors as an initial option.

Posner said, however, that when factoring the total cost of treatment and the cost of treating the myriad of side effects including osteoporosis, diabetes and others, that the procedure in the long run may be less costly.

The physical shock and suffering of patients would appear to be significantly less with the new treatment. Other diseases such as rheumatoid arthritis, systemic lupus and type 1 diabetes may also benefit from this treatment, but more studies are needed.

Dr. Paul Konowitz, an instructor in Otolaryngology and a surgeon at Harvard, and a member of the IPPF Board of Directors, underwent this treatment under the direction of Ahmed in Boston.

"The protocol can, and is being



Dr. A. Razzaque Ahmed is an associate professor of oral medicine and diagnostic sciences at Harvard School of Dental Medicine, at Harvard University on the staff of the New England Baptist Hospital in Boston, MA, and Director of the Center for Blistering Diseases.

used now." Konowitz said. "There are other doctors around the country that are using Rituxan® and IVIG but the way that they have been used it has been much more random and not as part of any (approved) protocol."

"I know of several patients who received Rituxan® without IVIG and developed severe infections because their B cells were totally eliminated. By giving the IVIG with the Rituxan helps to replenish levels of antibodies since the Rituxan wipes out the ability of one's own immune system to make antibodies. Hopefully this could be an end to the use of prednisone long term. In the study, all patients were eventually (tapered) off prednisone totally. Although I was not a part of this study, I received prednisone initially, and then was treated with Rituxan® and IVIG. I'm now off prednisone and all other medications." Konowitz said.

"The next frontier is for this to become an accepted treatment for pemphigus and maybe pemphigoid. Much of this has to do with insurance as this is a costly regimen, so I think that more physicians will have to start using this protocol to demonstrate that this should eventually be covered by insurance." ●

Dr. Ahmed will be writing a review on his study for the next issue of the Quarterly.

"If [IVIg is] used correctly...it can produce long term remissions."

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