The 2007 Annual Meeting Wrapup

Nearly 8 pages of recap and pictures have been dedicated to our successful 10th Annual Meeting in Toronto, ON, Canada. Starts right here on page 1r!

PEM Friends Meet

Guests gathered at The Stables in Manchester, UK for an extended weekend See Page 10

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Tenth Annual Meeting Exceeds Expectations

This year we celebrated the 10th anniversary of our Annual Patient/Doctor meetings in Toronto, Ontario, Canada. By holding this year’s meeting in Canada, we were looking to give our partners outside the U.S. an opportunity to experience the expertise and camaraderie that our meetings offer.

As in past meetings, we opened with Dr. Grant Anhalt, Johns Hopkins School of Medicine, Baltimore, MD, giving an overview of the disease process to new patients. To give patients a comprehensive understanding of the disease process, Dr. Anhalt began by discussing the basics of the immune system and how it works and relates to pemphigus and pemphigoid. He informed us of the fact that autoimmune diseases as a group is the third largest group of diseases behind heart disease and cancer, with billions of dollars being spent every year in caring for patients. He talked about the difference classes of genes that are associated with our diseases, and what role they play in determining the disease process. Dr. Anhalt talked about the differences between PF & PV, BP and MMP, and between pemphigus and pemphigoid generally. He gave a basic approach for treatment and how therapy is targeted.

He also explained a little bit about the Phase I drug trial that Peptimmune initiated several years ago, and the hope that they will soon begin the second phase of the study sometime soon.

The meeting officially opened at 9:00 a.m. with an introduction by Dr. David Sirois, President of the IPPF’s Board of Directors. Dr. Sirois thanked all supporters and participants and gave Dan Goodwill, IPPF Board of Directors, a Certificate of Appreciation for help in organizing the meeting. Dave also talked about the research the IPPF is helping to fund on definitions and disease outcomes. He closed by thanking all our supporters and participants.

The next speaker was Victoria Carlan. Victoria is a patient with pemphigus and is very interested in starting a Foundation in Canada. She provided a survey to determine how many members of the audience think that a Foundation in Canada would be an important step for Canadians. Victoria thanked the IPPF staff, Board, Dave Sirois, and all speakers. She specifically wanted to give a special

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From the Top
David A. Sirois, DMD, PhD
President, IPPF Board of Directors

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The View from Here

Janet D. Segall
IPPF Interim Executive Director

Annual Meeting

I want to say how sorry I am that I was unable to attend the meeting in Toronto especially since it was the anniversary of our 10th meeting. After watching the video, I could see what a terrific meeting it was. Dr. Neil Shear did a fantastic job of hosting. Everyone I spoke to could not say enough about his humor and presentation. I also want to thank all the speakers: Drs. Scott Walsh, Grant Anhalt, Ani Sinha, and Dave Sirois; Sandra Knowles, Pharmacist, and Robin Silverstein, Nutritionist. Thanks also to Alan & Gloria Papert, Greg Wright, Marilyn Targnosky, Victoria Carlan, Sonia Tramel. And, last but not at all least, Will Zrnchik for keeping the meeting going smoothly.

Thanks to our Sponsors and all the participants. I will see you all next year!

Evolution of the Newsletter

This is the 50th issue of the IPPF newsletter. Back in March, 1995, when the first issue was created, it was “The PV Foundation News” and only 5 pages! It is amazing how far more creative and substance-wise this publication has become over the last 50 issues - spanning 12 years.

I remember sitting in my home office making the decision to write Issue 1. The Foundation (then called the National Pemphigus Vulgaris Foundation) had only been approved as a non-profit 501(c)(3) organization the previous October (1994). Of course, in those days the internet was unavailable on personal computers and we were all writing in DOS. But, in spite of that, little by little people found us through their doctors. I thought that the best way of keeping individuals informed was through a newsletter so the “The PV Foundation News” was launched.

With Issue 4, our first e-mail address – PVnews@aol.com, was published. As the internet developed and e-mail became the way to communicate, and along with an article on the Web, we became more visible. We wanted a more professional looking newsletter, so Steve Shapiro took over the job from Issue 8 to Issue 11. Steve did a marvelous job changing the look, and the newsletter became the Quarterly.

As we grew in size, with Issue 12 – Spring of 1998, Sal Capo, with his amazing writing skills, became our new editor. He gave The National Pemphigus Foundation’s Quarterly, a new and better professional look. Sal continued writing and editing the newsletter for several years. Matt Cole took on the responsibility of producing the newsletter for several more years – giving it the look it has today. Since late 2004, Will Zrnchik has taken charge of the newsletter. We have received many accolades from individuals and other organizations on the high quality of our newsletter.

Because our diseases are so rare, I never think there will be sufficient material to fill an issue, but we always seem to have more than enough. I am so pleased with the progress we have made as an organization and how successful our newsletter has become. The newsletter would not be the publication it is today without the skills of Steve, Sal, Matt, and Will Of course, without any doubt, it has been all our donors who have helped keep the Quarterly the best publication on pemphigus and pemphigoid anywhere.

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thanks to all the caregivers who help patient manage their disease. She acknowledged how without good caregivers, it would be so much more difficult for patients.

Our host, Dr. Neil Shear, University of Toronto, gave a general overview of the disease processes: general health status of patients, what expertise is needed, and what do patients need above and beyond the disease and drugs. He talked about the challenges of treating patients: finding the right drugs to use, intolerable side effects, and what the benefits and risks were. He stressed the point that primary care doctors and Dermatologists should work in coordination for the best outcome for patients. Dr. Shear believes that most patients can eventually have a good quality of life once good control of the disease is achieved. He described the different stages patients go through: denial, disbelief, anger. It talked about the frustration, fear, shock and isolation that often occur when a patient can’t eat, talk, or have to deal with people who don’t understand. But, he knows that most people get through it and that interaction with others who have lived through the process can be extremely helpful to new patients.

He highly recommends network or Foundation in Canada. He acknowledged and showed his excitement for the participation at the meeting of the University’s Residents. He wanted them to interact with patients because he believes that patient advocacy is a huge part of Resident training. He also believes that patients need good advocates and that doctors need to teach residents how to advocate for their patients.

Turning to research, Dr. Animesh Sinha, researcher from Michigan State, East Lansing, MI, talked about how research can pave the way to better treatment and potentially a cure. He focused on T-lymphocytes in the blood and how pemphigus starts and progresses. He explained how T-cells & B-cells work together in the immune system, and when the system breaks down it can cause autoimmune disease. Many diseases have similar pathways, and they are looking at multiple levels of disease – cells, genes, etc. Genetic factors and environmental factors work together to cause disease.

Dr. Sinha’s lab made some new findings with CD-8 T-cells. They found that they are important in remission, and they are trying to find ways to boost this population, that this may be a natural way to try and put the brakes on disease progression.

He reminded people about his online survey and asked everyone who hadn’t filled it out, to please do so. It would truly help his work.

Grant Anhalt, M.D. took the podium again to talk about ongoing clinical trials and what they mean to patients. He explained what a difficult problem it was to get trials going because of the rarity of the diseases. He talked about several trials that are ongoing: Infliximab – Remicade, rituximab, Enbrel and CellCept, and how clinical trials can help patients get approved by their healthcare insurance company once the study is completed. The CellCept study is international with most patients coming from Europe and Ukraine. These studies help patients get the drug in countries where it is not available.

The Anti-TNF drugs are in trial for pemphigus because some case studies show that they can work in pemphigus. There have been 2 case...
International Pemphigus & Pemphigoid Foundation

**Reports of successful treatment of Remicade and 2 reports on Enbrel.** A study will tell us whether or not they really work. The Remicade (infliximab) study is now at Duke in NC, Univ. of PA, Philadelphia, with an additional site of now at USC. Travel compensation for patients in the area is given.

The Enbrel trial is close to being filled, and there new biologics also being looked at. There is also a high dose Cytoxan study at Northwestern. They ablate the immune system with Cytoxan and then the patients own stem cells are transplanted back.

The next speaker was **Sandra Knowles**, Pharmacist from University of Toronto. She talked about common drugs side effects and drug interactions, and how they can be confusing. She explained that not all side effects mean you need to stop the drug. Sometimes you can reduce the dosage of the drug, but sometimes an interaction can cause you to change the drug.

She encouraged everyone to develop a good relationship with their pharmacist. It is important to ask questions: How does it work? How long does it take to work? How do I take the drug? etc.

Dr. Knowles discussed the difference between prednisone and anabolic steroids – steroids used to build up your body. She went over the side effects of prednisone and that they can come in different forms. Most people will develop some steroid side effects, but it is often related to the amounts of steroids you have to take, for how long, and how it is taken. Anything above 5 to 10 mg a day and anything longer than 3-4 weeks a patient will usually see some sort of side effect.

She stressed the importance of preventative medicine – bone density, exercise, Vitamin D & calcium. She also discussed the immunosuppressives and their possible side effects and drug interactions. She also suggested we do not to use some of the Ace-Inhibitors for blood pressure.

**Dr. Scott Walsh**, Dermatologist at the University of Toronto talked about infectious complications and therapies, and what to do about them. Infections can be caused by viruses, bacteria, fungi, and parasites. Some are common, some are rare. Infections usually show up when lesions go without treatment.

He described virus, bacteria and how they work on the body, and which ones were more common in immunosuppressed people; anti-viral medicines used on viruses and antibiotics used on bacteria. He explained that immunosuppressive agents are used to control blisters, but they make the immune system less able to fight infection. For immunizations – some vaccine are safe – but do not take live-vaccines because it could activate the disease.

He cautioned that cancers can develop in immunosuppressed patients. Cytoxan can increase the frequency of bladder cancer so watch for bleeding. Azathioprine can increase the risk of skin cancer while getting a lot of sun.

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...continued from MEETING, page 5

exposure. Lymphomas can also occur with suppressed immune systems.

After the lunch break, Dave Sirois, DMD, PhD, NYU School of Dental Medicine, spoke about wound care and pain management. He talked about how to deal with visible lesions. Try to avoid friction and horizontal shearing. Covering wounds can help reduce the impact of trauma and help prevent infection. Keep lesion moist. Do not use adhesives. Bandages with antimicrobial dressings – a new honey-based product was recently approved in the U.S. that seems to work well in pemphigus/pemphigoid patients. Look at dermatciences.com. They are a company that sells bandages. Apti-Med is the new honey-based product which can help with open lesions. Bradley pharmaceuticals also makes wound care and skin products.

He described signs of infections, and the best way to handle that. He explained that drainage is important. If there is a blister that is covered, do not break skin lesion. Sponge cleaning is probably the most effective way to be clean.

Robin Silverstein, RD talked next about nutrition and the importance of a healthy diet. She explained that a healthy diet must include protein, carbohydrates, fats. Glycemic index is a good way to judge blood glucose. Lower glycemic foods are better for most people and have health benefits. They increase HDL's and help you feel full longer. She mentioned food that might induce pemphigus or bring on symptoms. But she clarified by reminding us that nothing has yet been proven as to what foods we might avoid; that food triggers are based on an individual's sensitivities. And, anything in excess can be dangerous so everyone has to watch how much they eat of one thing.

Our final speaker for the day was Dr. David Sirois who talked about oral medicine, pemphigus and pemphigoid. He said that oral involvement should be taken lightly because the consequences of not treating oral lesions can result in a person losing their teeth and having severe gum problems. He mentioned the importance of maintaining oral hygiene and mentioned different topical medications to help with calcificatin lesions. He did say that patients can have dental implants.

As the meeting wound down, the winner of the 50/50 raffle pledged her winnings go toward the creation of a Canadian chapter of the IPPF.

There was applause and laughter as IPPF Director J. Gregory Wright, MBA, and the wife of our Boston Support Group Leader, Ms. Gloria Papert, called ticket after ticket. Strangely enough, all of our winners were from Canada. The winners of a free yoga DVD were Teresa W., Alvine R., and Yuka A. Winners of a one year subscription to Yoga Journal were Dr. Yuka A. (a dermatology resident) and Adam L.

However the room fell silent as Gloria pulled the most anticipated ticket of the afternoon - the winner of the 50/50 Raffle. Greg called out the seven-digit winning number slowly, with an almost theatrical tone, as the audience scanned over their tickets. “Zero-eight-zero-nine-six-six-six..one.” There was a brief moment in time while these numbers registered in people’s heads.

“That's me!” came from the left side of the room. Dr. Yuka A. (yes, that very same winner from earlier) stood up and smiled. As she approached Dr. David Sirois, President of the IPPF Board of Directors, the room applauded and cheered. That would not be the last continued on page 11...
Why Patients Lie to their Doctors

In one word: CONTROL, or the need to feel more in control, even if it is only subjective control. When people have conditions or illnesses which need treatment and usually a lot of prescription medications, there are often negative side effects over which they feel no control. There becomes a need to gain some semblance of control over the situation. Without the “feeling” of some control, it is easy to feel helpless. Let me emphasize that lack of trust in the doctor-patient relationship and lack of honesty will likely make the situation worse, not improve it. Who actually wants to take more pills or other treatments? It is a human reaction (not necessarily rational) to feel less sick or ill if there are fewer changes to the before diagnosis situation. More pills, higher dosages, more diagnostic tests and procedures, including blood work, all tend to cause the patient to feel less and less in control.

Because one of the most difficult aspects to having a chronic illness like Pemphigus or Pemphigoid is the lack of control patients often feel, this adds to the feelings of helplessness over the disease process itself. Patients may not even be consciously aware that they are not being totally honest with their physicians about symptoms, taking prescribed medications as needed, and feelings which can signify depression and/or other psychological conditions. Obviously it is critical for the patient to be honest with himself/herself. This is actually easier said than done. Some patients honestly believe they are being honest just because they were not asked a particular question (e.g., if the doctor didn’t ask if you were more tearful or having trouble falling asleep, you didn’t actually lie if you didn’t mention these changes). This is an easy predicament to fall into, especially over time; and, the frustration usually gets increasingly worse. Remember, doctors don't have crystal balls, so they depend on their patients to keep them current.

If you are a patient and don’t agree with your physician, you may want to seek a second opinion, but changing your protocol is NOT a decision to be made unilaterally by you. If you do make a unilateral decision, you may be asking for trouble. Besides the innate dangers of certain changes, you seriously jeopardize the doctor-patient relationship. Doctors are not always right, as we know, but you can always ask your physician to contact an expert in the field. The experts are usually gracious and helpful, and a phone call from your physician may go a long way. Having a doctor who is willing to work with the patient for high quality care will make you a “team” which will, in turn, make the relationship stronger.

Having said these things, some doctors are more defensive and arrogant than others. If the patient can totally trust the doctor’s clinical judgment, even if not feeling like a team, this may work for many. Try to keep the doctor-patient relationship a true and trusting partnership, but if this is not working there may be the need to leave that relationship and seek out a more compatible one. If we share our knowledge of our bodies (and perhaps share cutting edge medical literature and/or anecdotal information from support groups) we can be part of the decision-making process. Some doctors are more tuned into us and our knowledge than others, but it is critical with such serious illnesses to not “play games”. The give and take between you and your doctors will allow you to feel more in control. If there is not basic trust, the relationship will likely not work. It is not the doctor’s body, but the patient’s; the doctor needs to listen to you, but you must first get honest with yourself in order to be honest with anyone else, professional or otherwise. It is always a two-way relationship.

In my psychology practice I often…

continued on page 12…
The IPPF newsletter has been very helpful to my patients and for my own practice of medical dermatology. I have recommended it to every patient with pemphigus or pemphigoid that I have seen since I started. Each patient gets a copy of the latest newsletter and a recommendation to join the IPPF so that they can receive the many benefits of membership. The medical articles help the patients understand their disease. Equally important are the articles on dealing with the physical and emotional stress that pemphigus and pemphigoid produces, as well as testimonials on how others have coped with this stress. Announcements about meetings, support groups and pen pals have been important to my patients, and many have participated in such activities. Thank you, the board, and the rest of the staff at the IPPF for publishing such a helpful newsletter over the years. Keep up the good work!

Amit Pandya, MD
IPPF Medical Advisory Board Member

Great work and it keeps getting better with every issue!

Masayuki Amagai
IPPF Medical Advisory Board

One of the unique things about the IPPF newsletter is that it only contains peer-reviewed new information for patients rather than pharma-driven information.

The IPPF has done a remarkable job in helping our patients. The organization has provided patient support and information that has improved the health and well-being of most of my patients. This success is a direct result of the dedication and hard work of the founder and current officers and members. As a physician, I very much appreciate the help that my patients can always be assured of receiving from this fantastic organization. Finally, the IPPF has been an important and effective advocate for increased research to understand and better treat the blistering autoimmune skin diseases, some of our most severe dermatological conditions.

Congratulations on hitting the 50th issue milestone. For over ten years, the IPPF newsletter has been a source of knowledge, support and inspiration for Pemphigus and Pemphigoid sufferers around the world featuring stories on everything from diet to the latest treatments. The contact information has been a lifeline to many readers. Since my name is listed in the newsletter as a Heart2Heart volunteer, I have received many phone calls from folks across Canada and some from the United States seeking help with these challenging illnesses. I know from personal experience that the newsletter has helped many patients and their families. Keep up the good work!

John Stanley, MD
IPPF Medical Advisory Board

Congratulations to the IPPF for the 50th issue of the newsletter. It is a great resource for patients and care givers. Keep up the good work!

Animssh Sinha, MD, PhD
IPPF Medical Advisory Board

Congratulations to Janet, Will and Olga for the 50th issue!

Lee A. Heins
IPPF Board of Directors

The IPPF Quarterly keeps me plugged into the current events, latest research, and patient information as a supplement to the website.

Greg Wright
IPPF Board of Directors

The IPPF Quarterly keeps me well informed and is an important source of information for patients and care givers.

Neil Korman
IPPF Medical Advisory Board

I talk up the patient based newsletter with my pemphigus patients and many come to rely on the information in the Quarterly.

Professor Dedee Murrell
IPPF Medical Advisory Board

One of the unique things about the IPPF newsletter is that it only contains peer-reviewed new information for patients rather than pharma-driven information.
Local Support Groups in the News

Local Support Groups Do Make a Difference!
Contact us for information about finding or starting a group in your area at info@pemphigus.org

PEM Friends' Weekend Getaway "Spurs" Hope

by Carolyn Blain
Photos courtesy of Hermien Konings

This year, the PEM Friends ‘away weekend’ extended...somehow...from two nights to five! Friends came from America, Northern Ireland, Belgium and England. We were delighted that Hermien, who runs the Dutch Support Group, also joined us from Holland. Some stayed in a nearby hotel, whilst others stayed as our guests in the spacious house called The Stables, where we all got together for a meal on Friday evening.

I believe everyone will agree there’s such a special atmosphere at these ‘away weekends’. Maybe it’s knowing we all share a very special something in common, which in turn creates a certain bond even before we get to know each other a little more. There’s certainly a very happy and pleasant ambience and everyone is genuinely interested in each other. How rare it is to find that within a group of people, at least half of whom have never even met each other before.

Bargain shopping was the order of the day for Saturday, before dressing for our ‘gala’ dinner in the evening. This was held in our home, which is just opposite The Stables and we had a really lovely time together.

Unfortunately Sunday was ‘good bye’ for most guests. I spent the day over in The Stables, mainly making sandwiches of our local ‘oven bottom muffins’ for Friends to eat before they left or to take with them for the journey home.

On Monday, two well-known Friends, John and Edith, who were unable to come for the weekend, joined us for lunch – and I’m happy to say we sat around the kitchen table in The Stables chatting til early evening! They knew Terry wouldn’t be leaving til Tuesday, so they took this opportunity to see her again.

Raymond and I love to host these occasions as we see people arriving looking anxious, even frightened, but leaving with smiles on their faces and much of their self-confidence restored. That’s our greatest satisfaction and pleasure. We will host another weekend in late June 2008. Come join us!

The Stables is available for Friday and Saturday nights for PEM Friends, as our guests. Those wishing to stay for the week prior or after are welcome on a ‘commercial’ basis (see www.shortletsmanchester.co.uk).
The Crush Wine Bar

It’s Saturday evening. You are in one of the world’s most captivating and beautiful cities - Toronto. What do you do? Well if you were one of the 60 people at the Crush Wine Bar you had an evening filled with fine wine, excellent cuisine, and great conversation.

The Crush Wine Bar hosted the IPPF’s 2007 Gala Celebration Dinner and from the enormous shrimp appetizers on through to the delectable lemon tort, everything surpassed expectations. One attendee said, “I feel so pampered! Thank you for all of this.”

The atmosphere was one where everyone felt special and enjoyed the fabulous cuisine. Dr. Sirois took time to recognize the meeting’s speakers for giving their time to educate and inspire the attendees.

THE PATIENT PANEL

Sunday morning opened with Greg Wright, IPPF Board Member, hosting the event. He talked about his experience with the disease. Several participants agreed to sit in and talk about their own experiences. Those on the panel were Victoria Carlan, Alan Papert, Marilyn Targansky, Greg Wright, and Sonia Tramel.

The floor was opened up for questions. Most everyone felt that rest is very important when traveling. Some were feeling very self-conscious about their disease, but others agreed that there was no reason to be ashamed. The disease is not your fault, and that being open about the disease can sometimes put people at ease as long as you don’t overdo it. Remember that you are not your disease – It is only something you have. Most agreed that it is was very important to take care of yourself first. Look at your life-style. Do things that can help your spirit and de-stress. That can often help in your recovery. Laugh a lot.

Caregiving was another subject that was brought up. Prednisone affects all family members and it will help spouses and children to remember that steroids can change a person, and try to realize that it is often just the drug.

It was mentioned that a good make-up to cover lesions is CoverFX at www.coverfx.com. Oatmeal (Aveeno Bath) baths can also be soothing.

The meeting then officially ended with applause and warm wishes to friends - new and old.

Victoria Carlan, Alan Papert, and Marilyn Targansky volunteered their time to sit on the Patient Panel and not only answer questions from attendees, but share their experiences with treatments and family matters.

In the coming months, different organizational models will be explored to see how to best set up the Canadian organization. Critical to its overall success will be a clear, sound relationship with the IPPF. As a small group of individuals struggling with these rare diseases, it makes sense to leverage each other’s strengths and pursue areas of mutual support. News about our progress will be available on the IPPF website and its newsletter. Stay tuned!

While creating a national organization for Canadians is underway, local efforts are also being pursued. For example, a local support group in Ottawa has been started and the first meeting will be on Tuesday, October 23rd from 7:00 p.m. to 9:00 p.m. Informational brochures will be sent to Ottawa dermatologists and details will be provided on the IPPF website’s Events Calendar. There is talk of rekindling the Toronto support group (which once had over 100 individuals). If you are interested in participating in the Ottawa meeting or would helping re-start the Toronto support group, contact Victoria.

A special thanks to IPPF staff for a great conference, the attendees who contributed thoughts, ideas, time, and resources, and to the 50:50 winner who donated her winnings to help kick off our fundraising efforts for this organization.

Victoria Carlan can be reached at vec@istar.ca
see patients who are resistant to psychotropic medications when they appear necessary. Many will not even consider going to a psychiatrist for an evaluation. Interestingly these are often the very patients self-medicating with over-the-counter (or other drugs) or other substances (e.g., alcohol or marijuana). This noncompliance is not helping them and may be hurtful. For example, alcohol is a depressant and will only make a depressed person more depressed. Also some of the popular herbal products sold at nutrition stores can actually be harmful. In autoimmune illnesses the body’s immune system is already working overtime against the body; clearly any alternative treatments which “boost” the immune system will not be in the patient’s best interests. Try to keep a list of all current medications and dosages, and keep it updated regularly. Sometimes pharmacists can be extremely helpful, especially if all your medications are in their computers. They can look for possible drug interactions. Still, your doctors should be aware of any nutritional supplements you are even considering taking. Not discussing this is lying by omission.

Your knowledge and understanding of how your disease works and the most cutting edge scientific information will give you more power and control over the disease. We cannot predict how the disease process will progress, but if we stay tuned into our bodies, follow doctor’s orders, and continue to add to our knowledge base as time goes on and newer treatments emerge and appear to have positive results in other patients, we become our own best advocates. Being dishonest by omission or commission will only serve to hurt you in your journey toward recovery. You must first learn to be honest with yourself and this is not easy, especially for those who are not proactive or those who are passive-aggressive. If you are not being honest with yourself, you need to first work on this in order to be honest with your doctors or others. If possible, try to have at least one person you trust and with whom you can be honest enough to share information as a reality check.

Hopefully the information in this article will help you better understand how and why patients may lie to their doctors. Please use it to help improve your own health care now and in the future.

...continued from WHY PATIENTS, page 7

IPPF Recognizes its 2007 Annual Award Winners - Congratulations!

Winners go "above and beyond" to Help Patients and Caregivers

There are many people behind the scenes who make the IPPF what it is - a support organization that is supported by patients, caregivers, family members, and some of the best physicians in the world. Without the dedication, time, and support of these individuals the IPPF would not be where it is today.

Volunteer of the Year

Ms. Carolyn Blain of the United Kingdom is the 2007 Volunteer of the Year. Carolyn has been instrumental in pemphigus and pemphigoid patient support in the UK as leader of PEMFriends. This past June, Carolyn and her husband hosted a weekend getaway at their ranch for patients and their families. The IPPF is glad to have Carolyn as an active member of the Foundation and we congratulate her as the 2007 IPPF Volunteer of the Year.

Outstanding Service & Support

Mr. Lee Heins was honored as the 2007 IPPF Outstanding Service and Support Award winner. Lee, a longtime member of the IPPF Board of Directors, has been the backbone of the Foundation’s financial planning as Secretary and Treasurer of the Board. The distinctive accomplishments of Lee reflect great credit upon himself and the IPPF.

Special Recognition Award

For over two years now, the IPPF has had the honor of having some great names in the pemphigus and pemphigoid community working on our Definitions Committee. The Committee, led by Dr. Victoria Werth with Professor Dedee Murrell, has been charged with standardizing the naming convention for pemphigus and pemphigoid diagnosis and treatment.

Carolyn Blain leads the PEM Friends UK Support Group.

Lee Heins is the Secretary and Treasurer of the IPPF Board of Directors.

Doctor Victoria Werth and Professor Dedee Murrell were recognized by the IPPF for their work on the Definitions Committee.
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Like a Breath of Fresh Air
Lanolin Helps BP Patient "Moisturize, Moisturize"

by Esther Friedman

It was in April, 2004, that I had been diagnosed with bullous pemphigoid, after noticing itchy blisters, yet again. When I learned...what was this? bullous pemphigoid? (I thought my dermatopathologist had sneezed - I had never heard either word of my diagnosis, before) - I went on the internet to learn more about it. That's how, back in April, 2004, I had found the IPPF.

It humored me to read that both "bullous" and "pemphigoid" mean "blister". That's me: "blister, blister", during a typical flare. What prompted me to see a dermatopathologist, with my April, 2004 flare, was that previously, a dermatologist had told me, during a less severe outbreak, "Your skin is dry. Moisturize. Moisturize." Thanks. In my April, 2004 outbreak, I had about 30 blisters in a 3 inch square area, around my right inner ankle.

Shortly afterwards, I noticed, while reading the IPPF "Wound Care Fact Sheet", under "Bandaging", to treat pemphigus and pemphigoid lesions, it suggests Vaseline can be used to keep wounds moist. Actually, I've found something even better than Vaseline. It is lanolin. I learned this when I'd been nursing my babies many years ago, where sometimes I'd get sore. Vaseline is inorganic, lanolin's organic. Using Vaseline equates to putting creal plastic wrap on a wound: the skin can't breathe, therefore it takes longer to heal (days, a week, or more). But, smooth on lanolin and the rawness, and the sore itself, are gone so much more quickly.

Example: Some years ago, I had been visiting my sister-in-law, a pediatrician, and my nephew, a 4 year-old, in wintery Boston. Josh had some redness all around the outside of his mouth, where he had been licking, after he had gone outside, one day. Ellen would frequently apply Vaseline to the soreness, but, she complained, it had been days, now. The irritation, unfortunately, was slow in going away.

I suggested that she try lanolin. "Where am I going to get it?" Ellen asked. "I have some with me," I replied, giving her my tube. She wasn't sure it'd help, but she decided to give it a try.

It was just a few hours later that Ellen remarked with surprise, "Esther, the redness is gone!" "Yes," I replied. "His skin can breathe through this. Lanolin's an organic product - wounds heal much faster than with inorganic Vaseline." Ellen was tickled and said she'd buy some of her own.

Another instance: My daughter had been visiting me early in April. She told me, one evening, her lips were chapped - do I have anything for them? I smiled and showed her the lanolin. She had become used to using "Chapstick", which is why the next morning she had stated with glee, "Mom, my lips are not chapped, anymore!"

Note that lanolin, opposed to Vaseline, smooths on easily only after it's warmed, some. Typically, I warm it on my clean fingers (remembering that neither lanolin nor Vaseline are sterile), before applying it to the sore spot. Or, I gently dab on a little ball of lanolin to the sore spot and smooth it over, a bit. A third choice may be to warm a little bit in a closed container, floating in warm water.

Another tip: I've found, before I buy lanolin, it's best to call the drug store and ask the pharmacist if s/he has some in stock. Many drug stores don't keep much, as Vaseline is a better seller: it's easier to apply.

The pharmacist may also ask if you're saying you want a product with lanolin as one of the ingredients. No - just lanolin itself, thank you. It comes in a tube, and also, in a jar. Pick which one you prefer. The pharmacist may have to order it for you - another reason I prefer to call, first.

Oh, and there's hydrous, and, anhydrous lanolin. You most probably know the difference is with, and without, water whipped into it. I'd guess the kind I've always used has been anhydrous as I've never seen any water seep out in the jar or from the tube. My current jar doesn't mention it.

With healthy wishes, Esther (EDFried- SW@aol.com).

Moisturizing is an important part of dialy skin care. The use of lanolin and other moisturizers may not work for everyone so make sure you check with your physician prior to adopting any treatment or therapy.

If your situation worsens while using any topical ointment, cream, or lotion then stop using the product and contact your doctor for further assistance.
"Coming Soon to DVD..."

We have all heard it on television or radio - “Coming soon to DVD...” Now the IPPF is following suit. The 2-disc DVD set of the 2007 Annual Meeting is in the final stages of production and will be available in October 2007. The two DVDs contain all the speakers and their presentations from the 2007 Patient’Doctor’s Meeting in Toronto.

As the pictures here show, each presentation includes the actual video of the speaker along with their slides so you can follow along with ease. Short clips are available online at www.pemphigus.org. Simply click on the 2007 Meeting Recap on the home page or look under Meeting Reports in our Article Archive.

While the IPPF has offered copies in the past, this is the first year we are pleased to present them in a very user-friendly format complete with video, audio, and the slides. They are being produced in-house in efforts to keep the quality high and the cost low.

The goal is to provide those who could not attend a chance to learn from the experts and share in the educational experience.
Centric is a nationwide organization with proven expertise in serving the specialized health care needs of individuals with rare and chronic, genetic disorders, as well as their families. To best serve these patient populations, we also reach out to involve patient advocacy groups, clinicians, health care payers and pharmaceutical companies through our business model called Patient Centered Health Management. It is through this unique and progressive model that we deliver and monitor prescribed therapies and specialized health management services to affected individuals.

Peptimmune is a clinical stage biotechnology company utilizing both novel and proven technologies to improve the therapeutic management of chronic autoimmune and metabolic disorders. They are developing second generation therapeutics that are expected to result in safer and more effective products with reduced development and marketing risks.

Talecris Biotherapeutics discovers, develops, and produces critical care treatments for people with life-threatening disorders in a variety of therapeutic areas including immunology, pulmonology, and hemostasis. Their mission statement is "To provide innovative biotherapeutics that enhance life and create value for our patients, employees, communities, and investors."

Crescent Healthcare, Inc.

Crescent has nine clinical centers in the country and is a leader in the alternate site infusion market. Our experienced pharmacists and infusion nurses provide a full spectrum of infusion therapies to patients throughout the nation. Our expertise in chronic therapies such as IVIG and Remicade is recognized nationwide. We also care for patients requiring acute therapies like antibiotics, enteral nutrition, and parenteral nutrition.