10th Annual Meeting Date Approaches
Destination: Toronto

The IPPF invites you to join us in Toronto, ON Canada as we celebrate our Tenth Annual Patient Meeting! Pemphigus and pemphigoid experts will be on hand as they discuss current and future treatments and medications as well as offer insight into the diseases.

We will hold a Friday night Welcome Reception at the Summer Residence (89 Chestnut) located on the University of Toronto campus. Saturday there will be discussions and sessions. Presenters will include Dr. Neil Shear and Dr. Scott Walsh, some of Canada's best experts on pemphigus, and from the U.S., Dr. Grant Anhalt. Saturday’s event will culminate with a wonderful dinner where relaxation, good food and wine will be enjoyed by all.

Sunday morning we will conclude our discussions and sessions with the entire event ending around noon.

Don’t Visit - Vacation!

Make Toronto your summer vacation destination! Summer brings several interesting and fun attractions to Toronto so why not take advantage of the IPPF room rate and stay a few extra days!

Visit the Caribana Festival which features the culture of the Caribbean with food, music and dance. The Rogers Chinese Lantern Festival boasts 30 elaborate grand-scale lanterns from China.

Just outside of Toronto in Elora is the Elora Festival with breathtaking performances of classical, jazz and contemporary music in impressive surroundings such as historic boutiques and the Elora Gorge.

Take a day tour to Niagara falls with spectacular views you will never forget. Visit the Toronto Zoo or if you are a Hockey fan, you can’t beat a visit to the Hockey Hall of Fame.

If you love to walk through history, visit some of Toronto’s famous museums: The Royal Ontario Museum is the largest museum in

continued on page 10…
The View from Here

Janet D. Segall
IPPF Interim Executive Director

The meeting in Toronto is almost here. Don’t forget to register now. You don’t want to miss this exciting yearly event. Remember, if you are not a Canadian resident, and you are flying to Toronto, you need a passport. If you are driving (of course this applies only to US residents), you need your birth certificate and a picture I.D.

These meetings provide us with the opportunity to interact with leading physicians treating pemphigus and pemphigoid. It gives us a chance to meet those who have been successful in managing their disease. And, we can learn more about our disease process, treatments, and lifestyle issues. It can also encourage our support network to grow which, in turn, helps patients.

Speaking of our support network, I am happy to say that it has grown considerably in the last year and a half! We have a substantial number of Heart2Heart members, new organizations have developed in Australia, Israel, and the Netherlands. This year, PEM Friends out of the UK has grown leaps and bounds with a great turnout and much credit going to Carolyn Blain. Remember Carolyn is hosting a weekend event in Manchester this June.

More people are joining our Heart2Heart section (we still need more so think about signing on). Our e-mail discussion group hosts over 300 people and our new interactive website with our discussion forums bring together patients from around the world helping one another. We even have a forum for pet owners.

We have also developed a forum section for Medical Professionals which we hope will grow as doctors and researchers start seeing the potential for better patient care. I still hear about way too many cases of patients getting treated by doctors who are unfamiliar with the disease. This causes a lot of bad outcomes with often lengthy resolutions. We hope the addition of our Medical Professional Forum that this will increase both awareness and knowledge within the medical community.

Your help is important. Our Summer Fundraiser letter will be at your door soon. We ask that you kindly send a donation to make sure the work we are doing continues. Finally, if there is anything we can do to serve the community better just call or email us and we will be glad to help.

CORRECTION!

Due to an administrative oversight, some names were omitted from the 2006 Donor Listing (Issue # 48):

Dr. Bert Konowitz
Dr. Paul Konowitz
O’Connor, Davies, Munns, and Dobbins, LLP
Melvin Zaret

While it is unfortunate, it does happen and we do apologize.
The Internet is a wonderful thing. From its inception it has been a medium connecting people from around the world with one another. On the recent success of the new IPPF Website (see related article on page 4), the IPPF has launched a Discussion Forum dedicated to Medical Professionals that is moderated by members of the IPPF Medical Board.

This forum is built into the new website’s existing forum, but requires special access to view and post. It is provided to doctors, nurses, researchers, and medical students so they have access to world-renowned pemphigus and pemphigoid experts. This forum is not intended, nor will access be granted to patients offering medical professionals a secure, private place to discuss treatments, medications, and ask questions to further their knowledge and the benefits of patients everywhere.

To access the Medical Professional forum, simply register on the IPPF Website as a regular user. Then send an email or call the IPPF with your username, professional affiliation, and we will upgrade your access.

For more information, please contact the IPPF at (916) 922-1298 or at info@pemphigus.org.

IPPF Launches Medical Professional Forum

IPPF Support Continues

The IPPF continues to operate thanks to the generosity of people around the world. Without your support we would not be able to assist newly diagnosed patients as well as continued support for existing patients.

In comparison, the First Quarters of 2006 and 2007 show a slight decline, but we are hoping for a resurgence as we prepare for the 2007 Summer Fundraiser.

For more information, call our offices at (916) 922-1298 or log on to www.pemphigus.org and click on Support the IPPF.
IPPF Launches New Website Focused on Building an Online Patient Community

After Five Months of Design, Coding, and Tweaking, IPPF Website "Membership" is Growing by the Minute

by Will Zrnchik
Director of Communications

If you haven’t had the chance yet, I encourage you to visit the latest version of the IPPF Website at www.pemphigus.org. The redesign highlights our late 2006 name change and takes advantage of the growing trend in online communities. The site does require registration in order to access some of the features, but registration is quick and best of all - it is free!

The registration process requires you to provide some basic information which is protected by the IPPF. The only information viewable on the site is your username, city, state, and country (there are others you can opt to include that information, such as personal website, picture, and so on).

Once you register you will be sent a confirmation email. If you do not receive it make sure to check your spam folder. Click on the activation link and you will be taken back to our site and ready to access additional information on pemphigus and pemphigoid, the discussion forums, and your member profile and image gallery.

Why Change the Site?

After years of being an information site (commonly referred to as a brochure site), the IPPF decided to create an interactive site where people visit more often and have a reason to stay longer. Community-driven sites such as MySpace®, Friendster®, and others are becoming a part of our everyday culture. Growing from the Internet’s early days of USENET, Internet Relay Chat (IRC) and chat rooms, today’s sites have plenty to offer in the form of interaction, friendship, and expression. People go to these sites to connect with others and stay because of the features, friendships, and information offered.

There are communities dedicated to coffee lovers, religious affiliations, sports cars, and now - pemphigus and pemphigoid.

The Discussion Forum

The Discussion Forum is the place to interact with others. Once hosted on MSN® and moderated by the IPPF, we have placed the forum on our site to allow members to interact within the comfort of our community. In order to use the forum you must be a registered member of the site. Remember, registration is free.

After logging in, click on Discussion Forums in the Main Menu. Once there you will see the list of forums. In each forum you will find a list of discussion topics with individual responses. Join in! If you don’t have a question to ask, we’re sure there is one you can answer. If you are simply making a statement (not a reply to another posting) we recommend you create a blog entry instead of a forum posting.

Member Blogs

Blogging is everywhere online and it has become the modern version of spray painting on a subway car. Okay, maybe not that extreme, but it is a good way of expressing yourself. Our blogging system allows members to create a blog as sort of a diary that they

continued on page 6…
Surveys Provide Researchers With Valuable Information

Surveys are a great way of helping out researchers to gather much needed information in a short period of time that otherwise could take years to compile. Your assistance could help to help identify causes of pemphigus and pemphigoid or determine better medications and treatment regimens. The International Pemphigus & Pemphigoid Foundation has been requested by two leading pemphigus and pemphigoid researches to assist them in gathering data on these diseases. Professor Sarah Brenner (Sourasky Medical Center, Ichilov Hospital, Tel-Aviv, Israel) and Dr. Animesh Sinha (The Sinha Laboratory, Michigan State University, USA) are conducting follow-up surveys to help identify how the diseases form and how to better treat them.

MEDICATION SURVEY

Prof. Brenner recently concluded a survey that initially showed that pemphigus may be more common in women. Her latest survey focuses on the medications a person might have been on at the onset of their disease. Certain drugs have been reported to induce or to exacerbate pemphigus and bullous pemphigoid in some patients. It is important to keep in mind that this is a rare side effect and some drugs have been reported in only one or few patients. In those patients, the causative drug had been detected only by an immunologic assay.

The IPPF encourages you to take this survey even if you took the previous one. You can access this survey on our website at www.pemphigus.org and click on the Surveys link in the Main Menu.

RISK FACTORS AND TREATMENT

The Sinha Laboratory at Michigan State University is working with the International Pemphigus & Pemphigoid Foundation (IPPF) to learn more about disease-associated factors and treatment of Pemphigus and Pemphigoid. Their goal is to explore how various factors like gender, race, family history, and treatment affect the risks and seriousness of disease states. Your experience with pemphigus or pemphigoid disease will help us better understand how blistering skin diseases develop, and how to treat them more effectively.

You are eligible to participate in the survey if you have been diagnosed with any type of pemphigus or pemphigoid disease. The survey is an anonymous, online questionnaire that will only take 15-20 minutes to complete.

Although you may have donated blood previously, The Sinha Laboratory may be contacting you in the near future regarding donation of blood samples for our ongoing studies on pemphigus and pemphigoid disease. For more information on the research studies currently being conducted by the Sinha Laboratory, please visit their website at http://humanmedicine.msu.edu/dermatology/index.asp.

If you have any questions, comments, or need clarification, please contact the Sinha Laboratory at (517) 353-7728, PVstudy@yahoo.com, or: The Sinha Laboratory 4120 Biomedical & Physical Sci. Bldg. East Lansing, MI 48824

Your participation is essential for furthering understanding of Pemphigus and Pemphigoid disease. Our research efforts would not be possible without the continued support of the Pemphigus and Pemphigoid community.

You can access this survey via our website at www.pemphigus.org and click on the Surveys link in the Main Menu or by going directly to the MSU site at http://humanmedicine.msu.edu/dermatology/index.asp and you will be provided directions for accessing and completing the survey.

The IPPF hopes you can help with these research efforts. Thank you.
I WANT THE QUARTERLY!

Copy or cut out this form, print clearly, and return with your donation to:
IPPF • 1540 River Park Drive, Suite 208 • Sacramento CA 95815

☐ I have enclosed my tax-deductable donation of $50.00.
☐ I am under financial hardship. I have enclosed $______.

Payment (Do not send cash): ☐ Check ☐ Visa ☐ MasterCard

Card #: __________________________ Expiration Date: __________________________

Signature (REQUIRED): __________________________________________________________

Printed Name: ______________________ Date: __________

Address: __________________________________________ Telephone: _______________

State/Province: ___________________ Country: _______ Postal Code: ________________

Email: __________________________________________

Welcome to the IPPF Site Member Home Page. This page allows you to see the latest activity here on the IPPF Website. From Latest News to the Latest Forum Postings, you can find it here.

Latest Events
- Tue, Jun 19th, 2007 (10:00 AM - 5:00 PM)
  - IPPF Patient Lecture - September 2007
- Thu, Jul 26th, 2007 (10:00 AM - 5:00 PM)
  - 2007 Annual Meeting

Latest News
- IPF Site Member Home Page
- What do I need to do?
- A blog can be a blessing
- IPPF is notifying members by the National Association of Consumers with Intestinal Disease
- Responsive Skin disease
- IPPF Launch Medical Professional Forum

User Details
Every registered user has their own profile and can edit it. You can even upload a profile picture so others know who you are. You can also update your current information, view your user stats, see what you have posted, and host your own image gallery (size, quantity, and content restrictions apply).

The site is a living, breathing entity. We are monitoring its status daily. There are enhancements made to the site that are both visible and behind the scenes based on comments from users, updates in applications, and general modifications to improve the site overall. If you have questions or comments about the site, or for that matter troubles finding something or a question on how to use a feature, please call, write, or email us and we will be happy to help.

Above - The first week the site was online, 93 people registered with another 208 in April. May looks like it will be more of the same. The numbers prove that our community is growing!

...continued from IPPF WEBSITE, page 4

Should I Blog or Post in the Forum?

Simply put, if you want to get up on your soapbox and vent, rant, brag, or just talk about your recent trip to the beach - create a blog entry. If you have a question you want answered or have some information to share that is relevant to the pemphigus and pemphigoid community - post in the forum.

Above - The Members Only Home Page is a one-stop location for the latest happenings on the IPPF Website. It lists the latest news, most popular items, current events, blog entries, and forum postings. You will be directed there after logging in or you can access it at any time by clicking on Site Member Home Page from the User Menu.

Below - The Site Member Blogs are a place where you can express your thoughts, share your successes, and voice your concerns. Bloggers have the option of allowing others to comment on their blog entries or restrict them to viewing only.

Support • What’s New • How to Help • Where to Go

The IPPF...

...Bridging the gap between you and current information

Above - The first week the site was online, 93 people registered with another 208 in April. May looks like it will be more of the same. The numbers prove that our community is growing!
Psychologically Speaking
with Terry Wolinsky McDonald, Ph.D.
Licensed Clinical Psychologist
Dr. McDonald can be reached at tmcdii2@msn.com

Caregivers & Caregiving
Everyone Needs Their Oxygen

Being a caregiver can take many forms, and although it is sometimes voluntary many become caregivers by “default.” It is not an easy or well-compensated job, and there are times when every caregiver experiences feelings of guilt. Resentment can build easily toward this role, with anger directed onto the patient, projected onto others or turned inward. Caregivers are human. They will lose their tempers, say or do things out of resentment and exhaustion/frustration, or because of the situation. Just as it is for the patient, control over the situation is tenuous at best sometimes. This is why it is critical to allow yourself to accept that you are human and not perfect, and that you can and will make mistakes. You are not a bad person; you are just a person.

Caregivers also experience their own sets of symptoms – including feelings of being overwhelmed (stressed out), sleep problems (difficulty falling asleep, sleep continuity disturbance, early morning awakening), appetite and weight changes, tearfulness, loss of interest in things normally important, and compromised overall health because of a weakened immune system. When time is of the essence, people often give up perceived luxuries first, which are usually the things that are GOOD for them (e.g., hobbies, exercise, downtime, socialization). This has negative effects on overall health, and contributes to caregiver burnout.

If you are the spouse or partner of the affected party, you will be tested to the extreme. The dynamics of the relationship may change in unexpected ways. In general, if the relationship was a good one before it will remain good and many couples state they feel closer. If the relationship was experiencing difficulties prior to the illness, the relationship will be tested to the limit. There are times when people are unable to reconcile their differences. Breakups, separations and divorces may become a reality. Couples counseling may be enormously helpful in many of these situations. The primary area to be addressed is usually communication. Keeping lines of communication open is critical. When couples are able to communicate in positive ways then the outcomes improve dramatically.

The following metaphor helps to make this abstract concept more concrete: When on an airplane, the flight attendant explains where the exits are located, how to use seat belts, how the seat cushions may be used as flotation devices, and how to use oxygen masks. When explaining the oxygen, passengers are told that if they are sitting next to a young child, an elderly person, or an ill person they must first take the oxygen for themselves – because if they help the other person first they might no longer be there to help them later! In other words, it is not selfish to help yourself, but rather necessary. Caregivers must be reminded to take their own oxygen, which may mean taking time off, socializing, participating in hobbies, meditation, lunch out with friends, etc. If caregivers do not take care of themselves and “take their own oxygen,” they will not be able to give optimal care to others. Not having oxygen is not compatible with life. Remember that taking care of you is not selfish, but rather essential in care giving. This is a metaphor you will hear from me all the time, and I cannot emphasize this concept enough. Women tend to be the main culprits here, although it also affects men. I call it “socialized woman syndrome.”

In many cases nurses or professional caregivers can be hired by the hour to help take care of patients if friends and family members are unable or unwilling to share in the time-consuming and, at times, draining burden. Usually there are community resources available; if you need help, ask for it. No one gives awards for being selfless, and if you are overwhelmed by the responsibility no one will benefit in the long run. Some patients become more ill than others, and some situations are more difficult than others. Many patients are also caregivers. I call it the double whammy.

The illness takes a toll on the caregivers and the patients. Chronic illnesses are usually “equal opportunity.” Sometimes it can be difficult to feel human; there is an emotional roller coaster from the illness and from the medications used to treat it. There will be times when the medications change a patient’s personality. Again, it is critical to keep communication open between the caregiver and the patient. Make sure you are on the same page; don’t take anything for granted. Misunderstandings and miscommunications can make difficult situations intolerable. This is why two-way communication is often the key. From a mental health perspective, it is extremely helpful for caregivers to check out any depression which may manifest itself as anger, isolation, agitation, irritation, sleep or appetite changes, feelings of hopelessness or helplessness, and even despair. Many hospitals, com-

continued on page 12...
"Paging Doctor Howard, Doctor Fine, Doctor Howard..."

Save the Comedy Routines for TV; Find the Doctor That is Right for You

The title comes from the Three Stooges' short "Men in Black" (1934), in which the trio play doctors. The short, a parody of MGM's Clark Cable movie "Men in White," poked fun at the medical profession. "For Duty and Humanity" is the pledge the Stooges made when they play medical students who have graduated with the "highest temperatures in their class." Those three always put a smile on the audience's face no matter how serious the issue was. However, finding a doctor that knows how to diagnose and treat pemphigus or pemphigoid is no simple task.

Because pemphigus and pemphigoid are rare diseases, it is often difficult to find a doctor who might be experienced in treating these diseases. There are several steps that could be taken to help you find the right physicians (see Finding the Right Physician, this page).

Most blistering diseases are treated by dermatologists even if there are only mucous membrane manifestations. Patient with only ocular pemphigoid should see an ocular specialist, preferably at a major medical center. You should first check with the IPPF. We have an extensive list of experienced doctors. However, our list does not cover all the areas of the United States or worldwide.

Remember, when you are looking for a doctor to help you, consider using the helpful tips provided on this page and always call our offices first. We're here to help.

1. Contact the IPPF for a physician referral.
2. If the IPPF cannot recommend a referral, check in your area to see if there is a University Medical Center – a teaching hospital. Teaching hospitals are usually places where you will find a doctor familiar with treating rare blistering diseases.
3. Decide what qualities you need in your physician – what is most important to you: knowledge, bedside manner, willingness to involve you in treatment decisions, etc.
4. If you live in a small town, call local Dermatologists first. The IPPF can recommend experts for your local doctor to consult with so you will get the best treatment advice available.
5. When you call to make an appointment, you might have to wade your way through the registration operators (chances are they do not know anything about pemphigus or pemphigoid). Make sure you do not underplay the need to see the doctor ASAP. Ask if you can talk to the nurse associated with the doctor if you cannot get a timely appointment. Time can play a big part in deciding on medication dosing.
6. If you are having trouble getting an appointment within a few weeks, call the IPPF. If the organization has a relationship with the doctor we may be able to help secure an appointment for you sooner.
7. In the U.S., check with the American Academy of Dermatology at www.aad.org/public/searchderm.html. They can help you find a doctor in the U.S.
8. The IPPF does have referrals for patients outside the U.S. However, the IPPF may not have one in your area. Check with the largest Medical Center in your city or country.
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

LA Group
Fires up the Grill in SoCal

by Sonia Tramel

The Los Angeles Support Group had a BBQ at the home of Sonia Tramel in Long Beach (CA) on Saturday, April 28. With over 35 people in attendance (including spouses and children), it was our best showing to date. It was wonderful to meet several new faces whose names were familiar to us from the phone list. A big “thank you” goes to head chef extraordinaire Roy DeViso (San Diego). Lee Heins (Irvine) headed up a meeting that covered such topics as last October’s New York meeting, the upcoming meeting in Toronto, and the importance of medications to prevent osteoporosis. We also discussed the importance of individuals, family, and friends financially supporting the Foundation.

This was our second BBQ and several members said that this was their favorite way to have a meeting. We are looking forward to our next meeting. If you are interested in joining the LA Group contact Sonia at stramel@speakeasy.net.

IN-MI Group
Starting to Grow

by Sonja Matheny

The IN-MI Support Group held a great meeting Saturday, April 21, 2007, in Kalamazoo, MI. There were 5 people in attendance along with a couple of guests. They shared their history, frustrations, successes, and tips on treatment. Bonding was the most important part for the group as they all know how hard it can be to face this disease. Putting faces to emails was one of the great things that came out of this meeting.

They have grown from 3 this fall to over 6 this spring and are planning another meeting in August. If you are out there and would like to join, please contact Sonja at 574-286-8540 or s_matheny@sbcglobal.net.

PEM Friends (UK) Gather in London to "Celebrate"

by Carolyn Blain

PEM Friends (UK) met on the 23 February 2007 in London for one of their informal lunches. We always meet on the top floor of Peter Jones, Sloane Square where there’s a spacious and pleasant self-service restaurant. We move tables and chairs to create a large square and are there for hours and thankfully, no one bothers us.

Fifteen Friends came along in February. Always one or two new people and many old pals. There is somehow such an upbeat and happy atmosphere. I think it’s everyone showing an interest in, and helping each other which makes these events so beneficial for all. No finer therapy in my opinion.

At one point we’d been hunting for additional chairs and a lady sitting nearby must have overheard and leaned across to tell us we were welcome to take the other chair at her table. I went over for it and - how’s this - she asked me what we were celebrating!!! D’you know, it gave me such pleasure to hear that. I then explained why we were there and she was perplexed to say the least, but said how good it was to see how happy everyone appeared to be despite their major health problems. We asked her to join us, but she couldn’t stay.

Whilst I’d travelled down to London from the north west of England, I do take these opportunities to stay with one of our sons and his family. However, three other people also travelled from the north west - this sort of commitment is just wonderful.

Our next opportunity of being together is the forthcoming 4 day long weekend over the 29 June. My husband Raymond and I offer complimentary accommodation for up to 16 people (squashed in, mind you!) in the largest of our luxury self-catering holiday homes (www.shortletsmanchester.co.uk), The Stables. Others have kindly volunteered to pay for themselves at a nearby hotel.

If you are interested in joining the PEM Friends (UK) Support Group or would like more information on their upcoming events, please contact Carolyn at carolynblain77@hotmail.com.
Canada, the Art Gallery of Ontario “an international cultural landmark,” and The Textile Museum of Canada which hosts 12,000 textiles that span almost 2,000 years and 200 world regions.

Location

The meeting is being held in Toronto ON, Canada at the University of Toronto’s 89 Chestnut Summer Residence. This is where we are holding the Friday night reception as well as the meetings on Saturday and Sunday. It is located at 89 Chestnut Street, directly across the street from the Metropolitan Hotel.

Saturday Night Dinner*

Saturday night’s dinner will be held at the famed Crush Wine Bar. Join us as we come together with friends and family at one of Toronto’s hot spots. Known for its atmosphere and selection of fine wines, the Crush Wine Bar is the perfect place for the IPPF and our friends to gather and celebrate.

Our reception will begin with a wine bar and hors d’oeuvres (brie d’Or, Vegetable Spring Rolls, Poached Shrimp, and Roast Sirloin Beef). Dinner choices include Pave of Organic Irish Salmon, Game Hen a Mattone, or a Vegetarian Plate. All meals will include dinner wine, soup, salad, and dessert.

Just a short cab ride from the meeting site, the IPPF Dinner at the Crush Wine Bar is an event you won’t want to miss out on. Seating is limited so get your reservation in early as this event will fill up fast!

*Cost is in addition to meeting registration fees. Menu items subject to change.

Lodging

The IPPF has blocked a limited number of rooms at The Metropolitan Hotel for a reduced rate. Our room block is open until June 27, 2007 and guests are welcome to call at any time to make reservations. Please note, you CANNOT reserve your room using the hotel’s Online Booking System. You can either call in or email them directly. Please note reservations must be made under the room block of International Pemphigus & Pemphigoid Foundation or quote INTER room block, in order to receive the special rate of $140.00 CAD per night.

The Metropolitan Hotel

$140.00 CAD/night
108 Chestnut Street, 1-800-668-6600
(416) 977-0707
reservations@metropolitanhotel.com

89 Chestnut Summer Residence

The price is right if you don’t mind sharing a television with other guests. At $99.00 CAD/night the location can’t be beat (remember, our meetings are being held at this location).

$99.00 CAD/night
89 Chestnut Street
(416) 977-0707
http://89chestnut.com

Registering for the Meeting

You can call the IPPF at (916) 922-1298, you can download a meeting registration form from our website at www.pemphigus.org, or you can also register online on our website. Again, our website is www.pemphigus.org.

Currency

Canada uses the Canadian Dollar (CAD). You can use an online currency converter to estimate what costs in Canada are in relation to your home currency.

Canadian Entry Requirements

EFFECTIVE JANUARY 23, 2007, individuals arriving in to Canada by air must have a valid passport. For more information go to http://www.cbsa.gc.ca/E/pub/cp/rc4161/rc4161-e.html and click on Visitors to Canada. You can also call the Canadian Border Patrol at 204-983-3500.

...continued from MEETING, page 1

Will Zrnchik, IPPF Director of Communications, and Mary Lee (Texas) pose for a photo op at the Gala Celebration Dinner. Guests enjoyed music and entertainment at the Water Club Restaurant during the 2006 Patient’s Meeting held in New York, NY.
Dr. Sarah Brenner and her staff have compiled a list of drugs that have been reported to induce or to exacerbate pemphigus and bullous pemphigoid in some patients. However, this list is not a recommendation to stop a drug without consultation with a physician.

It is important to keep in mind that this is a rare side effect and some drugs have been reported in only one or few patients. In few patients, the causative drug had been detected only by an immunologic assay.

### Medication Listing

**Chelating agents:** Penicillamine (Cuprimine, Depen)

**Antihypertensives:**
- **Calcium channel blocker:** Nifedipine (Adalat, Procardia)
- **Ace Inhibitors:** Captopril (Captoten, Captopzide), *Benazepril (Lotensin, Lotrel) Enalapril (Lexxel, Texzem, Vasotec, Enaladil), Lisinoprol (Prinivil)
- **Beta blockers:** Propranolol (Inderal, Inderide)

**Antiarthritic:** Gold sodium thiomalate (Myochrysine), Thiopronine, Mercaptopropionylglycine

**Antithyroid:** Thiamazole (Tapazole)

**Antioxidants:** Bucillamine, Pyritinol

**Antibiotics:**
- **Penicillin:** Amoxicillin: Trade names: Amoxil; Augmentin; Larotid; Polymox; Trimox; Wymox
- **Ampicillin:** Trade names: Omnipen; Olycillin; Principen; Unasyn
- **Azlocillin:** Trade names: Azlin
- **Bacampicillin:** Trade name: Spectrobid
- **Carbenicillin:** Trade name: Geopen
- **Clocxacillin:** Trade names: Cloxapen; Tegopen
- **Cycloxacillin:** Trade name: none
- **Dicloxacillin:** Trade names: Dycl; Dynapen; Pathocil
- **Methicillin:** Trade name: Staphcillin
- **Mexlocillin:** Trade name: Mezlin
- **Nafcillin:** Trade name: Unipen
- **Oxacillin:** Trade names: Bactocill; Prostaphlin
- **Penicillin G:** Trade names: Bicillin; Crysticillin; Megacillin; Wycillin
- **Penicillin V:** Trade names: Beepen; Betapen; Lederocillin; Pen Vee K; V-Cillin; etc.
- **Piperacillin:** Trade name: Pipracil
- **Ticarcillin:** Trade name: Ticar
- **Cephalosporines:** Cefadroxil (Duricef)

**Antituberculosis:** Etambutol (myambutol)

**Analgesic:**
- **Paracetamol:** Trade Names: Anacin-3, Bromo-Seltzer; Darvocet-N, Datri; Exceldrin, Liquiprin; Lorcet, Mapap; Neopap; Panadol, Percogesic, Percoset, Phene, Sinutab, Tylenol, Valadol; Vicodin, Abenol; Anaflon, Ben-U-Ron, Doliprane, Geluprane, Panadol

**Dipyone (Optalgin):**

**Nonsteroidal anti-inflammatory (NSAIDS):**
- **Piroxicam (Feldene):**
- **Aspirin:** Trade Names: Aggrenox; Alka-Seltzer; Anacin, Ascriptin, Aspergum, Coricidin D, Darvon Compound, Ecotrin, Empirin, Equagesic, Excedrin, Fiorinal, Gelprin, Halfprin, Measurin, Norgesic, Percodan, Robaxil, Soma Compound, Talwin Compound, Vanquish, Diclofenac (Arthrotec), Voltaren, Solaraze gel

**Antiparkinsonian:** Levodopa (Sinemet)

**Hypnotics:** Phenobarbital (Luminal, Barbita, Solfoton)

**Contraceptive:** Progesterone. Trade names: Delta-Lutin; Duralutin; Hylutin; Pro-Depo; Prodrox, Amen; Curretab; Cycrin; Provera, Megace, Aygestin; Micronor; Norlutin; Norlutate; Nor-QD, Ovrette, Gesterol 50; Progestaject

**Antidiabetic:**
- **Glibenclamide:** Glucotrol, Metaglip, Glibenese; Glipid; Glyde; Melizide; Minidab; Minidab; Minodiab
- **Metformin:** Avandamet, Glucophage, Glucovance, Metaglip

**Biologic response modulators:** Interferon, Intrleukin-2, Imiquimod (Aldara)

**Antiglaucoma:*** Latanoprost (Xalatane)

**Antipsycotic:** Haloperidol (Halidol, Peridol)

**Vaccines:*** Hepatitis B vaccine (Energix B)

**Anti duodenal ulcer:** *Famotidine (Pepcid, Famodil, Gastr

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**IPPF NOTE**

The ones depicted with an asterisk (*) were identified by the Sourasky Medical Center, Ichilov Hospital’s Department of Dermatology (Tel-Aviv, Israel) as problematic according to their professional experiences. **This does not mean they will affect everyone the same way.**
munity agencies and places of worship, offer support groups for caregivers. Give yourself a break: You need it and you deserve it. If you feel guilty, think of this as a “red flag” that will drag both of you down. Caregivers must not give up activities which give them pleasure. If anything, this is the time to start new hobbies or exercises! Build your own support network if one does not already exist.

Depression and “burnout” are realities in caregiving situations. You are experiencing a loss, just as the person you are caring for is. Although they share that feeling of loss, the caregiver often feels that they need to be the strong one in order to hold the situation together. Give in. Accept the fact that you are human – not superhuman – and that you can’t be there all the time or even every time you are needed. Recruit help. Remember, this does not make you weak; it makes you human!

In my own psychology practice I work with caregivers almost as much as I work with chronically ill people. After intake and a few initial intense sessions where both support and education is offered, in addition to validation, we decide together if weekly or more frequent sessions are needed. Sometimes this is enough, and sessions are only scheduled as needed. Cars receive routine maintenance and inspections. Why shouldn’t people receive evaluations and help (e.g., “tools” to help in particular situations)? Most people go to their primary care physicians for annual exams. They don’t wait until something is horribly wrong to request help. Prior to the 1950’s most people only saw the dentist in order to pull a tooth or treat a problem. A particular toothpaste company (Hey, baby boomers: do you remember “brush it, brush it, brush it?” It was a catchy tune!) teamed up with the American Dental Association and did radio and television ads to normalize the idea of yearly check-ups. Now most people do “preventative” maintenance and go for yearly exams.

It is unethical for a psychologist to treat the caregiver and the person for whom the care is being given in separate sessions; however, it is ethical (and usually insurance covered) to have sessions with both people together when requested by the patient/client. Often after a few sessions the caregiver may be referred to a group or offered that service if the therapist has an appropriate group running at that time. Groups offer something which individual therapy cannot: group members take care of each other on many levels. However, a note of caution: Often a caregiver is not ready for a group initially and may need a couple of individual sessions first, or maybe just an evaluation or screening. I generally prefer to screen people before placing them in a group. Groups for caregivers can be life savers. If you have the courage to verbalize your feelings you will receive amazing support and validation from others. When someone else expresses feelings similar to yours – especially negative feelings – you will feel validated. Often strong bonds and friendships are formed within these groups. The caregiver realizes that they don’t have to get through this experience alone.

Online caregiver groups may also be very beneficial. This being said, all support groups are not the same, and finding the right one which is a comfortable fit may be quite challenging. The good news is that groups are out there and are readily available; groups can, however, be counterproductive. If it doesn’t feel right, then it probably is not right for you. Sometimes group facilitators don’t adequately do their jobs of guiding, setting boundaries, and reminding people about confidentiality. In groups no one can ensure confidentiality; there are specific ways to properly facilitate, and not everyone is well trained or trainable! It is always good to do your own screening – perhaps having the opportunity to talk to the group facilitator and also at least a couple of group members, if possible. Ask trusted people, facilities, or insurance companies for recommendations. Do your own research. Also, depending on...

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**Caregivers: Ask Yourself...**

1. Why am I doing this? (Is this totally an act of unselfish love, or is this something I feel obligated to do?)

2. Is this getting easier, or harder, with time?

3. Have the dynamics of the relationship changed? (Is the relationship stronger and more loving? Have you felt “put upon” or manipulated and unappreciated? Are you harboring anger?)

4. If you are not able to “be there” emotionally with the patient, are there other ways you can help? Are there specific errands, cleaning, grocery shopping, or other chores which will show support in a different but more concrete way?

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UK Derm and Staff Take Part in "Walk for Skin" Fundraiser

Walk Supports British Skin Foundation and their Efforts

from University of Manchester News

Leading dermatologist Professor Chris Griffiths and his team took part in the 2007 Walk for Skin on May 20th at Tatton Park, Knutsford, UK. The walk benefits the British Skin Foundation, an organization that support 18 UK charities fighting against skin disease. One of these charities is the IPPF's PV Network. The walk encompasses two weekends and is the largest multi-charity fundraiser for skin disease in the United Kingdom. It takes place at venues all across the UK.

Professor Griffiths, of the University of Manchester's School of Medicine, and many of his researchers and nurses from the Salford Royal NHS Foundation Trust walked three miles around Tatton Park as part of the Manchester leg of the event.

Prof Griffiths said: "We are supporting the Walk for Skin because 8 million people in the UK suffer from skin diseases many of which have unsatisfactory treatment. The British Skin Foundation has been instrumental in supporting pioneering research work at the University of Manchester and this is our opportunity to support them in their fund-raising work."

Over £160,000 was raised at BSF's first ever Walk for Skin in 2006 and four new venues were added in 2007. Celebrity supporters include actor Nitin Ganatra (Charlie & the Chocolate Factory and Bride & Prejudice), and UK television personality Olivia Nash, MBE (Member of the British Empire).

For more information, please go to the British Skin Foundations's website at www.britishskinfoundation.org.uk

CLINICAL TRIAL ANNOUNCEMENT

Is IVIg Effectiveness Improved by the Concurrent Administration of Cyclophosphamide?

The purpose of the trial is to determine if IVIg effectiveness is improved by the concurrent administration of cyclophosphamide. There is evidence it can, but a trial is required to be sure.

Background

The trial is important, not only to improve the treatment of pemphigus but also to improve the effectiveness and reduce the need for this very expensive treatment.

Enrollment Criteria

- Age 18-65 and on at least 20 mg/day prednisone
- Pemphigus antibodies in a titer of 80 or more
- One or more of the following:
  - Persistent disease activity while on steroids
  - flare in disease activity while tapering steroid doses
  - failure of established lesions to heal
  - complications to conventional therapy

Patients with renal insufficiency, stroke or pulmonary embolism are excluded.

Trial Details

All patients entered into the trial will be treated with a standard regimen of IVIg (4 cycles, 2 weeks apart). Additionally, half of the patients will be randomized to receive a standard dose of cyclophosphamide. See IPPF Note below.

Contact Information

Dr. Jean-Claude Bystryn
NYU School of Medicine
(212) 263-7333 or bystryn@nyu.edu

IPPF NOTE:

Dr. Bystryn will accept any insurance to cover the cost of care that goes along with the trial. The drugs are not covered by the trial, but should be covered by insurance. If you are interested in this trial, your insurance would have to cover the cost of the drugs. Dr. Bystryn will take that insurance for the visits associated with the trial. Contact his office for more information.
### IPPF MEETING REGISTRATION FORM

**NAME:** ____________________________________________________________________ **AGE:** _____________

**ADDRESS** __________________________________________ **# of Previous Conferences Attended**

**CITY** __________________________________________ **STATE** __________________________________________ **POSTAL CODE** ____________

**COUNTRY** (if other than United States) ___________________ **PHONE** ____________________

**EMAIL** __________________________________________

☐ I require special assistance (please attach a written description for all persons with special needs)

Please list names and ages of other guests who are attending.

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<th>Name</th>
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Cancellations are not refundable after July 23, 2007.

### All registrations must be received by the IPPF no later than JULY 15, 2007.

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<td>TAX-FREE DONATION TO FURTHER SUPPORT OUR EFFORTS</td>
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<td>MEETING SCHOLARSHIP DONATION (help someone in need attend this year’s meeting)</td>
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☐ I request scholarship assistance. Please call me immediately and accept this donation to help defray costs.

**GRAND TOTAL** $

**Check** ☐ **Money Order** ☐ **Visa** ☐ **Master Card** ☐

Card # _____ - _____ - _____ - _____ - _____ - _____ - _____ - Expiration Date: _____ / _____ Postal Code: __________

Name on Card ____________________________________________ Signature ____________________________________________

Please make my tax-free donation in HONOR / MEMORY of ________________________________ (circle one)

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

Please notify them at the following address:

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Send payment in full to:

IPPF 2007 Annual Meeting, 1540 River Park Dr Ste 208, Sacramento CA 95815

or fax to (916) 922-1458

All payments must be made in US currency and must accompany this form.
The International Alliance of Patients’ Organizations (IAPO), which the IPPF is a member, in collaboration with the Non-governmental Organization (NGO) Health Committee recently held a landmark meeting at the United Nations Headquarters in New York on Patient-Centered Healthcare: Aligning Healthcare Systems with Patients’ Needs. New York Support Group Leader Matt Koenig attended as the IPPF representative.

The meeting successfully raised awareness of Patient-Centered Healthcare at an international level, generated considerable support for the patient-led IAPO Declaration on Patient-Centered Healthcare, and a number of recommendations for future action.

A wide range of speakers from different international and professional backgrounds, led by patient representatives, convened to discuss the meaning and application of Patient-Centered Healthcare on a global level. Their thoughts were addressed to a diverse audience of healthcare policymakers, professionals and patient organization representatives, to further understanding and support for the drive to put patients at the centre of healthcare systems.

The essence of patient-centered healthcare is that all healthcare systems be designed and delivered to meet all the needs of patients. It is an ambitious undertaking, and there are many obstacles, but the global imperatives for success are undeniably vital for people worldwide.

From the pemphigus and pemphigoid perspective, we are lucky to have educational sources such as the IPPF website, a virtual community of patients, doctors, and related health professionals. The IAPO is striving to create similar sources of information and support throughout the world for all manner of health and personal welfare issues. To both their advantage and disadvantage, they have billions of people to reach out to.

For additional information on the IAPO, visit their website at http://www.patientsorganizations.org

(Source: http://www.patientsorganizations.org/pchmeeting)