2008 ANNUAL MEETING LOCATION ANNOUNCED!
The 11th Annual Patient/Doctor Meeting will be held in Dallas, Texas, USA from April 4-6, 2008.
See page 3 & Inside Back Cover

WAITING...
Nobody likes to be kept waiting. Dr. McDonald has some advice to help you. See Page 7

What's Available & How to Participate
Current Clinical Trials

Clinical trials are a great way for patients to help researchers gather much needed information. Many times there is only so much that can be done from a research standpoint without volunteers. The following are a few of the ongoing clinical trials and who to contact for more information. You can also find out more by logging on to our website at www.pemphigus.org and clicking on the Clinical Trials & News link in the Main Menu.

The use of KC706 for the Treatment of Pemphigus Vulgaris

The purpose of this trial is to (a) determine the ability of KC706 to prevent the appearance of new blisters and heal existing blisters, while maintaining stable doses of corticosteroids and/or immunosuppressants, in patients with pemphigus vulgaris (b) to determine the safety of KC706 and (c) to access the plasma levels of KC706.

Background
KC706 is a new class of agent that could offer hope to patients in healing and preventing pemphigus lesions. Patients with PV have antibodies directed against proteins called desmogliens, which serve as a “glue” between the layers of skin. The study will assess the effects of the experimental drug KC706 to interrupt the activity of these antibodies, thereby preventing the skin from forming blisters.

Current treatments have multiple side effects therefore there is a high unmet medical need for treatments with fewer side effects. Dr. Rubinstein’s, from UNC Chapel Hill has developed an animal model of pemphigus vulgaris. When used in this animal model, KC706 prevented the occurrence of blistering.

Enrollment Criteria
Patients must be at least 18 years of age, with active PV skin, scalp or mucosal lesions and a diagnosis of pemphigus vulgaris confirmed by skin lesion biopsy. The patients must be taking and require either stable doses of corticosteroid therapy or immunosuppressive therapy or both. Pregnant or nursing women are not eligible to participate in the trial. All potential participants will have a screening visit which will include a review of their medical history, and a blood draw to determine their eligibility to participate in the study.

continued on page 4…
The View from Here
Janet D. Segall
IPPF Interim Executive Director

In this Holiday Season we are asking for your support so we can continue to help patients from around the world get the information and the care they need. This past year saw exciting progress in disease treatments with the use of rituximab, an ongoing clinical trial for CellCept, and a new trial for PV with infliximab. Autoimmune disease research is continuing with new drugs being developed that could show promise for people with pemphigus and pemphigoid.

The IPPF recently supported the “Pemphigus Disease Area Index (PDAI) and the Autoimmune Bullous Skin Disorder Intensity Score (ABSIS) for Use by Dermatologists.” When this study is completed, dermatologists will uniformly have a better way of describing our diseases. This will help make disease progress clearer to patients.

Our new website has been a spectacular success. Patients from around the world can talk with each other through our forums, and doctors unfamiliar with our diseases treating patients now have the opportunity to communicate with experts to find out more. But, there is still more we need to do. We need to support research. We need to make sure patients get the best care possible. We need to help patients understand their disease and alleviate their fears.

The IPPF staff and network of support groups, doctors and friends make a difference in helping patients and medical professionals. You or someone you know is living with pemphigus or pemphigoid. We need your generous support to help the IPPF perform its work on behalf of all patients living with our diseases and those who are yet to be diagnosed.

Our community needs to work together to accomplish our mission. In the spirit of holiday giving, please help us maximize the success of this important opportunity by sending a generous donation to the IPPF. Help us by encouraging your friends and family to contribute to this noble cause. Send a check, or donate online at www.pemphigus.org, but please Donate Now! Your donation means hope for the future.

Reminder:

Presidential and Congressional elections are only a year away. These are going to be important elections in deciding which direction healthcare and research will go. These are very significant issues for all of us living with and dealing with pemphigus and pemphigoid.

Make sure you know where your candidate stands and whether they represent your vision for the future of healthcare and research. Make sure you weed through the propaganda before you vote because there is and will be a lot of untruths and misinformation in this media driven world. Visit your candidate’s websites because that is where the best information will reside on individual decisions.

I don’t know how involved any of you are in politics, but I do encourage everyone to vote next November. It can make a difference.
IPPF Announces our 2008 Annual Meeting Site: Dallas!

The IPPF Annual Patient/Doctor Meeting moves up the calendar to April

Few cities can boast a rich history at such a young age. Just over 150 years old, Dallas, Texas has been a home to cowboys on the trail, oil and railroad tycoons, and football dynasties. Now you can enjoy this beautiful city as the University of Texas Southwestern Medical Center opens its doors to the IPPF.

Dr. Amit Pandya, IPPF Medical Advisory Board and Professor of Dermatology at UT, is the event’s primary clinical coordinator this year. Joining Dr. Pandya from the IPPF Medical Advisory Board will be Dr. Animesh Sinha, Dr. David Sirois, Dr. Victoria Werth, and 10-time Annual Meeting speaker Dr. Grant Anhalt. The IPPF is also pleased to announce that several Texas-based physicians will be sharing their knowledge with patients from around the world.

We welcome all new patients to our Patient Orientation and Information session with Dr. Grant Anhalt. Saturday’s topics will include updates on research and clinical trials. We will talk about the drugs and their side effects; and the best way to live successfully with our disease. Sunday’s session will be for patients and caregivers only. We can discuss how we feel about our medication (and our care), what choices we make to help ourselves live better with our disease, and how we can help each other.

Rooms are being held for us at the Renaissance Dallas Hotel, 222 Stemmons Freeway (214) 267-4852. Our Friday night “get-together” reception, complete with an authentic Texas dinner buffet, will also be held at the Renaissance. Room rates for the IPPF block are just $99 a night.

While in Dallas, take the Southfork Ranch Tour, home of the television series “Dallas.” As well, visit the Book Depository Museum which depicts the events around the assassination of JFK. Dallas has terrific theater, or visit Scarborough Village, a sixteenth century themed festival with 10 entertainment stages, and hundreds of performers.

REGISTER NOW, LEARN FROM THE BEST, AND ENJOY A GREAT SPRING WEEKEND IN THE SOUTHWEST!

Search Begins for IPPF CEO

The IPPF is pleased to announce it has started its search for new leadership to guide the Foundation to the next level. Dr. David Sirois, President of the IPPF Board of Directors, said, “this is an incredible opportunity and responsibility” and that 2008 promises to be another year of accomplishments for the Foundation.

Following the success of the IPPF Growth Campaign and the partnership with Centric Health Resources, Inc., the position of CEO will be responsible for membership growth and retention, entrepreneurial approaches to increased revenue, fundraising, oversight of strategic initiatives in public and professional awareness and education, research promotion, patient advocacy, corporate, and government and public relations.

If you, or someone you know is interested in the position, please submit their cover letter, resume and compensation requirements in MS Word or Adobe PDF format no later than January 15, 2008 to careers@pemphigus.org.
...continued from CLINICAL TRIALS, page 1

**Study Conduct**

3 months of treatment, assessments of efficacy and tolerability every two weeks, with a four week follow-up.

**Contact Information**

If you are interested in participating in this trial or referring a patient, please contact:

**University of Pennsylvania**

Principal Investigator: Victoria Werth, M.D.
Clinical Coordinators: Joyce Okawa, R.N.
Phone: 215-898-0168
E-mail: joyce.okawa@uphs.upenn.edu
or
Matt Rose
Phone: 215-898-0108
E-mail: Matthew.rose@uphs.upenn.edu

**New York University School of Medicine**

Principal Investigator: Bruce Strober, M.D. Ph.D.
Clinical Coordinators: Judy Wang
Phone: 212-263-5244
E-mail: Judy.wang@med.nyu.edu

**Florida Academic Dermatology Centers-Cedars Medical Center**

Principal Investigator: Francisco Kerdel M.D.
Clinical Coordinators: Ray Guevara
Phone: 305-324-2110
E-mail: fadcresearch@bellsouth.net

**Harbor UCLA Medical Center**

Principal Investigator: Michael Kolodney, MD
Clinical Coordinators: Rattapon Thuangtong, MD
Phone: 310-222-1845
E-mail: rattaponthuangtong@yahoo.com

**University Hospitals Case Medical Center**

Principal Investigator: Neil Korman, M.D.
Clinical Coordinator: Kelly Jeffords
Phone: 216-983-0861
E-mail: kelly.jeffords@uhhospitals.org

**University of Texas-Southwestern Medical Center**

Principal Investigator: Amit Pandya, MD
Clinical Coordinators: Christina Carrigan, R. N.
Phone: 214-645-8968
E-mail: Christina.Carrigan@UTSouthwestern.edu

**University of North Carolina- Chapel Hill**

Principal Investigator: David Rubenstein, M.D. Ph.D.
Clinical Coordinator: Trevor Presler
Phone: 919-966-1406
E-mail: Trevor_presler@med.unc.edu

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**NYU: Is IVIg Effectiveness Improved by the Concurrent Administration of Cyclophosphamide?**

- The purpose of the trial is to determine whether the effectiveness of IVIg is improved by the concurrent administration of cyclophosphamide for people with pemphigus vulgaris (PV). There is evidence that it can, but a formal randomized trial is required to be sure. 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.

- There is an increased risk of bladder and hematological malignancy associated with the use of cyclophosphamide. However, this risk is both dose and time dependent. Most reported cases of malignancy related to the use of cyclophosphamide occurred in patients on long-term and/or high-dose therapy. Risks were associated with a cumulative dose of >20 grams administered for at least one year (1) and the cumulative risk of bladder cancer is 3.5% in 8 years and 11% in 12 years following initiation of cyclophosphamide therapy (2). During the clinical trial for pemphigus, twelve patients will receive short-term therapy (12.5 grams cyclophosphamide over a 3 mo) which has not been reported to increase the risk of malignancy.

- During the trial, all twelve patients randomized to receive cyclophosphamide will be closely monitored for the development of side effects of therapy. Laboratory monitoring (CBC, LFT, UA) is performed every two weeks for the first month and then monthly until the end of the study. All patients will be asked to drink at least 3 glasses of fluid per day to minimize uroepithelium toxicity. And all patients with persistent microscopic hematuria, macroscopic hematuria, or grade 2 cystitis will discontinue cyclophosphamide therapy and be removed from study participation. We do not believe that study participation will increase the risk of malignancy due to the low cumulative dose of cyclophosphamide and patients will be continually monitored for side effect development.


**Contact Information**

If you are interested in participating in this trial or referring a patient, please contact:

Dr. Jean-Claude Bystryn
Professor, Department of Dermatology
NYU School of Medicine
(212) 263-7333
bystryn@nyu.edu

To make the trial more widely available, Dr. Bystryn will accept in full any insurance of patients that are enrolled into the trial.

The patients will be responsible for the routine charges associated with the treatment, as the treatments being compared are not experimental.

**Using Infliximab (Remicade) for the Treatment of Pemphigus Vulgaris**

The purpose of this trial is to determine the safety of infliximab for the treatment of patients with pemphigus vulgaris (PV). Secondary clinical endpoints include the number of days to cessation of new blister formation, the ability to reduce prednisone to 25% of the initial dose by week 18.

Infliximab is a TNF-Inhibitor. TNF’s primary role is in the regulation of immune cells. Infliximab

*continued on page 11...*
Remembering Captain Jack

Sailor who battled PF, Cancer "returns to the sea"

by Janet Segall

Back in 2002 I took my first trip to Waikiki, Hawaii. On that trip I met a fascinating couple, Jack and Loretta Campbell. A long time friend flew in from the Big Island where she lives to meet me. The Campbell's picked us up and took us to our hotel and invited us for dinner at their home in Waikiki. They were the most gracious hosts, and we had a wonderful time.

I was very saddened to hear from Loretta this past July that Jack had passed away. Although I talked with him a few time, and only met him that once, I was so impressed with his love for life I wanted to profile Jack this issue and all his lifetime accomplishments. The information was provided to me by Loretta, and from my meeting with them back in 2002.

Jack was born in Butler, PA, on May 10, 1927. He was an Eagle Scout and graduated from the U.S. Naval Academy in 1953. He had two commands as Captain of destroyers, and received numerous citations and medals, including the Legion of Merit.

In 1977, at the age of 50, Jack retired from the Navy holding the rank of Captain. After retiring, he sailed by himself and one deck hand to Tahiti. Upon his arrival in Tahiti, Loretta met him there and they sailed the South Pacific for 12 years on a 35 foot wooden sail boat, the VENTURE, with no radio, no refrigeration, and no means of communicating with the outside world. They visited the islands of the American Samoa, Tonga, Fiji, Noumea, Australia, New Guinea, Guam, Japan, and finally returned to the U.S. in August 1990. By this time they we both in their 60's.

In 1997 Jack was diagnosed with pemphigus foliaceus. Jack kept and worked on VENTURE until he was 75 years old, at which time his pemphigus and the inability to spend much time in the sun forced him to sell his beloved boat. He would trot off each day with sandwich in hand (he was not "allowed" to come home for lunch!!) and spend the day varnishing, painting, and gabbing with the other yachties.

Jack never had a "break" from his pemphigus and had many episodes where it was necessary to put "artificial" skin on his backside to enable him to sit down. He went through all this with a spirit only imaginable to most.

Jack was diagnosed with lung cancer over a year ago; the upper right lobe was removed and all seemed to be going okay. Six months later, the brain cancer was discovered and it was inoperable - 7 lesions in his brain. Through all this his attitude and demeanor were above reproach. He suffered greatly but still maintained his dry sense of humor. His wife Loretta said, "After a week in the hospital, I brought him home with the help of Hospice and he passed nine days later. Home was where he wanted to be. He was a true soldier - if I can use that word for a life-long naval officer!"

I talked with Jack a few months before he passed away, and was so impressed with his attitude and demeanor in spite of what he was dealing with. I absolutely can say to Loretta that there was no doubt in my mind that he was a true soldier.
Dr. Sergei Grando, longtime blistering disease researcher and clinician, has moved from University of California, Davis in Northern California to the University of California, Irvine in Southern California. Although he will be missed in Sacramento, there are very few experts in the Southern California area. This will give patients in Orange County the chance to discuss treatment with an expert.

Dr. Grando was born and educated in Kiev, Ukraine, and received his M.D. from the Medical Institute, Kiev in 1980. He received his Ph.D. in Pharmacology and Biochemistry from the Post Graduate Institute for Physicians, Kiev (1984); and a Doctor of Sciences (D.Sci.) degree in Immunology and Cell Biology from the Central Institute of Dermatology and Venereology, Moscow (1989). He became Dean of International Relations of the Post Graduate Institute for Physicians in Kiev. This allowed him to freely travel to Western countries and meet with numerous academics. These trips and meetings proved very helpful to Dr. Grando, who, by then was an internationally recognized expert in autoimmune bullous dermatoses. In May, 1991, just before the fall of the Soviet Union, Dr. Grando, his wife and two small children traveled to the U.S. for a meeting with Dr. Peter Lynch, then Chairman of Department of Dermatology at University of Minnesota School of Medicine.

With Dr. Lynch’s help, Dr. Grando obtained asylum in the U.S. and has been in here ever since. He became an American citizen in 1999. Dr. Grando worked at the University of Minnesota until 1996 as an Associate Professor of Dermatology. He then joined the Department of Dermatology at U.C.-Davis. Dr. Grando’s research focuses on non-steroidal treatment of pemphigus and other bullous diseases. As a physician he is concerned about drug side effects from treating pemphigus, and is devoting his research efforts to finding alternatives to current therapies.

Dr. Grando has authored over 200 scientific articles, has been the recipient of research grants from the NIH and other granting organizations, and has been a featured speaker at numerous national and international meetings. Dr. Grando currently sees patients every Monday.

Information is key to living well with any disease. From time to time we like to provide our readers with some helpful information as well as remind them of other things that can make living with pemphigus and pemphigoid a little easier.

**Cover FX**

For people with sensitive skin, at our 2007 Annual Meeting, Dr. Neil Shear recommended Cover FX for use in patients with pemphigus and pemphigoid. If you are interested in this make-up check out their website at www.coverfx.com.

**Diabetes**

Watch blood sugar levels. Fasting glucose levels should be lower than 110 mg/dl. “A fasting blood glucose level between 100 and 125 mg/dl signals pre-diabetes. A person with a fasting blood glucose level of 126 mg/dl or higher has diabetes.” More information is at www.diabetes.org/about-diabetes.jsp

**Hypertension**

Normal blood pressure is less than 120/80. Stage 1 hypertension is when the top number (systolic) is 140-159, and the bottom number (diastolic) is 90-99. Stage 2 hypertension is greater than or equal to 160 systolic and equal or greater than 100 diastolic. Find out more at www.nhlbi.nih.gov/hbp/detect/categ.htm

**HDL**

HDL stands for high density lipoprotein, which is a form of “good” cholesterol. Lipoproteins are proteins in the blood that move cholesterol, triglycerides, and other lipids to various tissues.

In general, for men a HDL level below 37 mg/dL, and for women HDL below 47 mg/dL may increase the risk of heart disease. An HDL 60 mg/dL or above helps protect against heart disease.

The main function of HDL is to help soak up excess cholesterol from the walls of blood vessels and carry it to the liver, where it breaks down and is removed from the body in the bile.

**LDL**

LDL stands for low density lipoprotein, a type of cholesterol. High levels of LDL’s can cause arteries to clog. Good levels of LDL are considered between 100-129 mg/dL. LDL/HDL ratio seems to be the best indicator for a healthy heart. While 4.5 is considered a good score, the best ratio should be below 4.


Waiting...

How to cope with waiting for diagnosis, treatment, remission, flare ups, medical appointments, and more.

U nderstandably, many of you have voiced your own frustrations about WAITING. When frustrations build, stress builds, and it becomes a vicious cycle. The purpose of this column is to try to help in breaking that cycle. When I used to work in a hospital, performing neuropsychological assessments, I learned the hospital motto: HURRY UP AND WAIT!

I was one of the lucky ones then, without a lot of doctor appointments and the clout to ask the doctors’ offices to just page me on my beeper when they were ready for me, since I could be paged directly and be at the doctors’ offices within minutes. Now that I work in private practice in another location, I have to rearrange my schedule multiple times/week and play the WAITING GAME just like everyone else. As per the Judy Collins song, I have seen the clouds “from both sides now”.

WAITING feeds into a patient’s view of “learned helplessness”, Dr. Martin Seligman’s explanation of one kind of depression. When multiple events seem to prove a person’s helplessness to change the situation, this feeling becomes internalized. Even patients who do not feel particularly depressed or anxious find it difficult and frustrating to WAIT – to get a timely MD appointment, to see the doctor (or perhaps nurse practitioner or physician’s assistant) or even wait for an important “call back” from the physician’s office. Then comes the actual appointment, the tests, the waiting for results of the tests, etc., which result in sleepless nights, agitation and frustration for both patients and care givers. Appointment times are not an exact science. When I go to a physician appointment I usually don’t have a lot of extra time; if the doctor is running very late and my problem is not emergent I let the office staff know when I need to leave. Sometimes I have to reschedule and leave. Make sure to take things to do, such as reading material, puzzles, knitting, or letters to write. Keep things in your car also, just in case of traffic problems, accidents, or other problems. Listening to certain music in the car may increase anger or road rage, while other music will be more calming. Everyone has certain favorites which may be helpful in difficult situations. For most patients with rare illnesses, just getting an accurate diagnosis in a timely fashion is very frustrating and difficult. By the time the diagnosis is made the patient is already “set up” for and feeling learned helplessness.

Some dermatologists are willing to set up regular appointments, even weekly if necessary, with a patient, since it is often easier to cancel an appointment at the last minute (if they are okay with this) than to try to fit a patient in for an emergency. If your doctor is willing to do this and you find yourself unable to get timely appointments when necessary, it is something you may want to discuss with your doctor. Maybe an once/month appointment would be helpful, depending on your own circumstances. Of course, emergencies cannot be predicted.

Another helpful piece of advice is to keep a running list of questions as they come up. If the questions are not emergent, just take the list with you to your next regularly scheduled appointment. It is helpful to check things off the list and to write down answers as necessary or to simply check things off the list. Make sure all the doctors know about any changes in medications, related or unrelated to the doctor’s specialty. Keep a list of medications up to date and make sure the pharmacy has all the medications in their computer. Recognize the importance of a Medic Alert bracelet. If you have one, keep it up to date. This helps both patients and doctors to have information current. It keeps frustration levels lower and keeps the doctors “in the know” which is best for patient health. This is a “win-win” situation. Will you still have to wait? Of course: That just goes with the territory of chronic illnesses. Acceptance of that will be helpful. Doctors are dealing with life and death matters all the time. They may care about patient frustration (or not), but keeping patients alive is supposed to be the first priority. Who would want it any other way, as frustrating as that may, at times, be? So, even with acceptance what else can a patient do to minimize waiting, which feeds into anger, depression, anxiety, and learned helplessness? Scheduling your appointment to be the first in the morning may be helpful, even if four people are scheduled for that time. Waiting is part of life. Who has not had to wait because of a late airplane, bus, train? With air travel, the experts also recommend scheduling an early morning flight, because the likelihood of it being more on time are increased exponentially. The first afternoon appointment is also likely to be closer to on time at the doctor’s office. Schedule accord-

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A Man & His Music: Another Profile in Courage

by Linda McKee

A profile in courage, it would seem, applies to everyone dealing with the various types of Pemphigus. In light of the fact that my husband is dealing in a positive way with his PNP, we were asked to write a bit about how he has dealt with this devastating disease.

So, for this article the profile in courage applies to my husband, Merv, and how he has dealt with the triple whammy of non-Hodgkin Lymphoma, toxic myopathy which nearly took his life, and finally his diagnosis of Paraneoplastic Pemphigus...the most rare variety and usually the most deadly.

At the time of his pemphigus diagnosis we had never even heard of it. We were so relieved that it wasn’t mouth cancer that we shared some joyful moments before getting home and researching the disease. What can one do faced with those odds but to ask many questions, find competent medical treatment, seek out answers and support (thank you IPPF), and deal with it on a daily basis as best we can.

After the initial shock wore off, and we found a knowledgeable and caring team of doctors in Boston, Merv became the subject of scrutiny for the various types of Pemphigus. In light of the fact that my husband is dealing in a positive way with his PNP, we were asked to write a bit about how he has dealt with this devastating disease.

He immediately immersed himself in his music which had always been a serious source of comfort over the years and a relaxation from his years as an electrical engineer. He has played the violin from a very young age and now prefers playing the viola. He has over the course of 50 plus years been involved in various musical groups, symphonies, quartets, in both England, where he grew up, and here in the U.S. All those years music was playing in his head as well.

So, after his diagnosis, he felt it was time to put some of that music he was hearing in his head onto paper, and a wind quintet was born. He heard of a world competition held in London and sent his quintet in. Several months later we heard that he was a finalist, and all 6 family members and 2 friends flew to London to hear the results. He came in second in the world! It was exciting and astounding. Most importantly it was the best encouragement for him to continue writing his music.

Soon after he and 2 others formed The South Shore Chamber Orchestra, and in the summer of 2006, his Windsor Suite debuted to a full house and standing ovation! It was also chosen as a piece for the Quincy Symphony Orchestra to play in the spring of 2007. The music continues to flow at a rapid rate and a new piece was again debuted in the summer of 2007.

We are sharing his story because one do faced with those odds but to ask many questions, find competent medical treatment, seek out answers, and deal with it on a daily basis as best we can.

His lips and eyes had become glued together and it took several days of extremely high doses of IV Prednisone for the lips to become unglued. At that time he had a few lesions on his body but for the most part the PNP is confined to his mouth...mainly cheeks and tongue. Despite being hospitalized due to Leukopenia after the vigorous chemo. sessions with Rituxan and lVig, he has somehow been able to maintain a positive outlook.

We leave off by wishing one and all many blessings and the courage to face all that lies ahead. We pray that all forms of Pemphigus will be a disease of the past before long. Let’s all work together to help make that happen. There is ALWAYS hope. •
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

Meeting in the Midwest

by Sonja Matheny

The Indiana-Michigan Support Group held a meeting at Das Dutchman Essenhaus in Middlebury, IN on October 20, 2007. What a great experience, sharing a family style meal. Nothing brings it all together than “passing the dish” - and the great tasting food that was served in the dish!

The total in attendance was 8 including caregivers (all spouses this time). We learned about our new member and the challenges he has been facing over the last 11 years. His wife has been very supportive of him.

Our spouses learned many things that day about us. They learned that we are “normal” - or as normal as anyone can be given our circumstances *wink*. Our spouses shared that it is extremely difficult for them when they see the pain, stress, and confusion we as patients are dealing with. A few also shared that we can be a little neurotic when on steroids but they still love us dearly!

Our group experienced great food, laughter, sharing, and a bond that forms when you meet each other face to face to discuss lives and life! Thank you to all who attended. If you are interested in our next meeting, please contact Sonja Matheny, IN-MI Support Group Leader, at s_matheny@sbcglobal.net.

Ottawa Has First Meeting

by Victoria Carlan

Ottawa’s first Pemphigus and Pemphigoid Support Group meeting was met with lots of interest but, unfortunately, a low turn out. While many called or emailed, only two people were able to attend the first “meet and greet”. Since I was one of them, I can honestly say that it was a helpful evening. There is something comforting in sharing your story and taking the time to listen to others. It reminds you that you are not alone in this.

I felt revitalized with new energy to get on with it – which for me meant to stop worrying and wondering when this will end and get out there and start living as much as possible.

The next meeting will be held on Tuesday, January 22, 2008. There will be a guest speaker to talk about wound management. The meeting will begin with a “meet and greet” followed by testing a variety of bandages with an expert and talking about issues related to caring for lesions. You can come to part or all of the session depending on your needs and interest.

The location of this meeting will be announced closer to the event. Because there will be a guest speaker, individuals are asked to confirm their attendance through the IPPF’s Events Calendar (found on its website).

As for news on establishing a national support organization, progress has also been slower than originally hoped. Individuals who attended the IPPF conference in July have been doing some independent fundraising. (Thank you to all who have contacted me to report on their successes.) Meetings are being held with the Canadian Revenue Agency to determine the best organizational and governance structure. A number of people from across the country have come forward offering their support and assistance. If you are interested, there are still many other opportunities to get involved. For more information, please contact Victoria at vc_pemphigus@istar.ca.

LA SG Has a Special Guest

by Barbara Roller

Dr. Jennifer Haley was the guest speaker on Octo. 13 at the LA Support Group Meeting held at Westside Pavilion. Dr. Haley was greeted by her “fan club” of patients who are treated at UCLA. Dr. Haley, a frequent speaker at the LA Meetings, talked about various treatments such as IVIG and Rituxan along with the positive results she is seeing. After a Q&A, Dr. Haley joined some members of the group for lunch.

For information on the LA Support Group and how you can help, please contact Lynn (lynntg@prodigy.net) or Barbara (barbara-roller@sbcglobal.net).

To see if a group is meeting in your area, check out the IPPF website and click on the Events Calendar.
If you are interested in starting a support group, contact the IPPF at (916) 922-1298.
UPDATE: Health Management Program

by Penny Bemus

As many of you know, the International Pemphigus & Pemphigoid Foundation has been working with Centric Health Resources, Inc. since April of this year to develop a health management program for patients with pemphigus and pemphigoid. If you were at the 2007 Annual Meeting in Toronto, you may have met some of the people from Centric who have been helping to develop the program.

Centric is a health services organization uniquely focused on rare, orphan disorders, with an innovative approach that integrates comprehensive health management with the delivery of specialized pharmacy services.

Centric has a process whereby it identifies disorders where health management would benefit, approaches the patient advocacy group with the idea, and develops the program in conjunction with the patient advocacy group members.

We are excited to announce that we have completed a comprehensive disease profile for pemphigus and pemphigoid which summarizes the current knowledge and thinking related to the diseases as determined and reviewed by key opinion leaders in the medical field.

The document was written by the IPPF steering committee members (Dr. David Sirois, Dr. Victoria Werth, Dr. Jean-Claude Bystryn, and Janet Segall) and reviewed by members of the IPPF’s Medical Advisory Board. The disease profile was used to develop the goals of the program.

The health management program focuses on seven key goals, which are to:

1) Achieve and maintain remission, and manage relapses
2) Reduce patients’ risks from prolonged or high dose steroid use
3) Decrease the number of adverse drug events
4) Improve patients’ oral hygiene, and improve early identification of nasal, laryngeal, and pharyngeal disease
5) Reduce occurrence or magnitude of secondary infection
6) Detect and improve stress levels
7) Improve quality of life and promote a healthy lifestyle

The program is designed to achieve these goals through a variety of methods, such as:

• Providing access to general information
• Educating patients about the disease, medications, and therapies
• Helping patients to communicate better with their health care team
• Encouraging patients’ compliance with their treatment plan
• Developing patients’ self-care skills
• Assisting patients’ coping, lifestyle, and service efforts.

Patients will be encouraged to develop an individualized care plan with their physicians, and participate in periodic patient assessments, personalized interventions, and health status monitoring delivered through a Peer Health Coach (PHC). PHCs are patients who are specifically trained in delivering these health management programs. Patients enrolled in the program will receive a phone from their PHC on a periodic basis (frequency depending on severity of symptoms), and may call their PHC any time if they would like to talk. The PHC will be trained to ask and

Health management programs are aimed at:

1) Providing patients sufficient knowledge to become active and informed participants in their own healthcare,
2) Proactively reducing risk and avoiding preventable complications, and
3) Providing care coordination and access to local and national resources

continued on page 14…
The Divisions of Dermatology at Duke University Medical Center, University of Pennsylvania School of Medicine, University of Iowa, and the University of Southern California are recruiting patients for a clinical study using infliximab (Remicade) to treat patients with pemphigus vulgaris who continue to have blisters, skin ulcers or other disease activity despite therapy with 20 mg/day or more of prednisone therapy. 20 patients will be treated with intravenous infusions of infliximab or placebo on weeks 0, 2, 6, 14 followed by monthly follow up visits through week 26.

Patients must be at least 18 years of age with a clinical diagnosis of pemphigus vulgaris and ongoing disease activity and on 20 mg/day or more of prednisone. Patients that are taking other immunosuppressive drugs such as azathioprine (Imuran), mycophenolate mofetil (Cellcept), methotrexate, or cyclosporine A will undergo a 4-week washout phase before beginning the trial. Pregnant or nursing women are not eligible to participate in the study.

Participants will have a screening visit which will include a review of their medical history, physical examination and obtaining of a blood sample to determine their eligibility to participate in the study.

Contact Information

Please contact the Division of Dermatology at any of the following locations closest to you by email or phone with questions regarding this trial and feel free to pass on this contact information to all interested individuals.

Locations

Duke University Medical Center
Durham, NC

Clinical Trial Coordinator
Deborah Hannah
919-681-5797 (phone)
919-684-3002 (FAX)
Deborah.Hannah@Duke.edu

University of Iowa
Iowa City, IA

Clinical Trial Coordinator
Marge Wolkimir
414-805-5313
mwolkimir@mcw.edu

University of Pennsylvania
Philadelphia, PA

Clinical Trial Coordinator
Joyce Okawa
215-823-4439
joyce.okawa@uphs.upenn.edu

University of Southern California
Los Angeles, CA

Clinical Trial Coordinator
Dr. David Woodley -323-865-0383 or
Dr. David Peng -323-226-3376
Fax: 323-865-0957

Duke University: Rituximab for the Treatment of Bullous Pemphigoid

The purpose of this trial is to determine the safety of rituximab for the treatment of bullous pemphigoid (BP). Secondary clinical endpoints include the number of days to cessation of new blister formation, the ability to reduce prednisone to 25% of the initial dose by week 24 and bullous pemphigoid antibody levels at week 24.

The Division of Dermatology at Duke University Medical Center is recruiting patients for a clinical study using rituximab (Rituxan) to study the treatment of bullous pemphigoid in participants who continue to have blisters, skin ulcers or other disease activity despite therapy with 17.5 mg/day or more of prednisone therapy. 8 participants will be treated with intravenous infusions of rituximab on day 1 and day 15 and followed monthly for 6 months and then every 3 months for a total of 1 year.

Participants must be at least 18 years of age with a clinical diagnosis of bullous pemphigoid and ongoing disease activity and on 17.5 mg/day or more of prednisone. Participants that are taking other immunosuppressive drugs such as azathioprine (Imuran), mycophenolate mofetil (Cellcept), methotrexate, or cyclosporine A will undergo a 4-week washout phase before beginning the trial. Pregnant or nursing women are not eligible to participate in the trial. All potential participants will have a screening visit which will include a review of their medical history, physical examination and obtaining of a blood sample to determine their eligibility to participate in the study.

Contact Information

Please contact the Division of Dermatology at Duke University Medical Center by email or phone with questions regarding this trial and feel free to pass on this contact information to all interested individuals.

Clinical Trial Coordinator
Deborah Hannah
919-681-5797 (phone)
919-684-3002 (FAX)
Deborah.Hannah@Duke.edu

What’s the Big Deal?

Clinical trials do more than just provide patients with free or low cost treatment and medication for a short time, they help researchers validate theories on certain medications and treatment protocols.

The IPPF is a strong supporter of clinical trials. By giving your time and providing the coordinator with honest feedback, it helps everyone affected by pemphigus and pemphigoid. Even if you don’t personally qualify for a trial, maybe someone you know might. Either way, the only way to better the lives of patients is through advancements in treatments and medications. If you can help, please do.
ingly, if possible.

Before moving to a condo I had a large home, and unless there was a total emergency I would try to schedule two or three deliveries and/or repairs for the same day – with the hope that at least one of them would actually show! Waiting and being dependent on others’ reliability is always problematic.

Remembering the above, about six months ago I was given prescriptions for two tests, which would have had to be scheduled separately in different departments on different days at the same hospital. I gave the matter some thought, and since the tests were not emergencies or life threatening I scheduled them in another facility a few months later with two other tests which I knew would be needed.

By scheduling several months in advance, I was able to get all four tests done at the same place on the same morning and be back at my own office a little after lunch time. I had never done this before, but it was a pleasure, and the other facility had no problem relaying all information to the doctors who had prescribed the tests. Sometimes I am able to schedule as many as three MD appointments in the same morning and still be at my own office by lunchtime. Of course this is not always possible.

Recently I had an acute knee injury and faced an unfamiliar staff at an unfamiliar hospital. Everyone was polite, but while I did have to WAIT many hours for the MRI I knew I needed, I actually insisted on waiting for this particular test. The staff would have preferred for me to be carried out and taken to an orthopedist, but I listened to my body which told me not to leave. I would be lying to say it was pleasant or that waiting 7 hours after the X-ray for an MRI was okay, but I kept myself busy “icing” the leg, trying to read, and making lists. I also listened to soothing music. (The MRI was worth the wait.) Although waiting is inevitable, how a person handles the wait can, and does, make an enormous difference.

WAITING is part of life, so we do have to find ways to deal with it. Just knowing that there are choices one can make about how to handle the waiting will affect mood and self-esteem. Waiting is not easy, but it is a necessary part of the human condition.

Start with small goals and changes. After experiencing some degree of success everyone feels more confident and less frustrated. Continuing to set and successfully master smaller goals allows the larger goals to be met successfully.

Try to stay realistic, and readjust goals as necessary. I readjust all the time. It’s not a perfect science, but it helps.●
answer patient questions, and will also be tuned in to what questions require referral to the patient’s physician. This component of the program will be done in full cooperation and collaboration with the patient’s physician.

The program will also include updated educational materials and a template for the individualized care plan. Other materials may include web- and print-based learning programs, current articles, findings, and advice from key opinion leaders.

What we hope to achieve is better health, improved quality of life, and better financial outcomes for everyone! We will track the achievement of the program’s goals over time, with the hope that within the next 3 – 5 years we have some great patient population data to work with for refinement and improvement of the program and to measure what is working and what is not (all patient data confidentiality will be properly maintained of course!). Then we can really start to increase awareness about conditions such as pemphigus and pemphigoid, which will hopefully encourage more funding and provide further research to find a cure!

The program is expected to be in the pilot phase in February, 2008 in preparation for launch in May, 2008. We will have a preview of the program at the April 2008 Annual Meeting in Dallas, TX. We hope that you are as excited about the program as we are and that you will provide your full support in our efforts.

...continued from UPDATE, page 10

Excuse me, I have a question!

A few questions from the 2007 Annual Meeting Q&A

Q. Will crushing prednisone and putting in a feeding tube still work?
It should work. Corticosteroids can work in different forms – pills, liquid, and IV as well

Q. Are there any foods with anti-inflammatory properties?
There are no foods proven to have anti-inflammatory affects.

Q. What is the best Toothpaste?
Avoid abrasive toothpaste – tarter control – keep it simple. Make sure the toothpaste has fluoride. If needed, use a prescription toothpaste like Prevident 5000 for people at high risk for dental decay.

Q. What is the anticipated time from onset of disease to remission, and if that remission is considered drug-free and durable?
Optimal treatment with limited disease would be someone on down to a low dose of prednisone in 9 to 12 weeks. That is with immunosuppressives as well. There are different disease activities. Majority of people do have life-long disease, but occasionally you will see someone with life-remission.

Ms. Penny Bemus, MBA, JD, is the Vice President of Business Development for Centric Health Resources, Inc. Penny’s diverse business background in finance, business planning and legal affairs has helped Centric and the IPPF move forward with this important program that will benefit pemphigus and pemphigoid patients.

For more information on Centric visit www.centrichealthresources.com.
**IPPF 11th Annual Patient/Doctor Meeting - Dallas, TX - April 4-6, 2008**

**IPPF MEETING REGISTRATION FORM**

**NAME:** ____________________________________________  **AGE:** ___________

**ADDRESS __________________________________________**

**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.

- Name ____________________________________________  Age ______________  Special assistance? □
- Name ____________________________________________  Age ______________  Special assistance? □

*Cancellations are not refundable after April 2, 2008.*

<table>
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<th>ITEM</th>
<th># ATTENDING</th>
<th>ITEM COST</th>
<th>TOTAL</th>
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<td>EARLY REGISTRATION <em>(Postmarked ON/BEFORE 2/15/2008)</em></td>
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<tr>
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<tr>
<td>TAX-FREE DONATION TO FURTHER SUPPORT OUR EFFORTS</td>
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<tr>
<td>MEETING SCHOLARSHIP DONATION <em>(help someone in need attend this year's meeting)</em></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 ___________________________

- Please notify them at the following address:

  **ADDRESS ____________________________________________**

  **CITY ___________________________**  **STATE __________________**  **POSTAL CODE __________**

  **COUNTRY (if other than United States) ____________________________________________**

  ALL PAYMENTS MUST BE MADE IN US CURRENCY AND MUST ACCOMPANY THIS FORM.

Send payment in full to:

IPPF 2008 Annual Meeting, 1540 River Park Dr Ste 208, Sacramento CA 95815
or fax to (916) 922-1458

**PLEASE SELECT YOUR COMPLIMENTARY SATURDAY LUNCH MEAL CHOICE(S)**

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<th>MEAL</th>
<th>QTY</th>
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<tbody>
<tr>
<td>Albacore Tuna Salad on Baguette with fresh whole fruit, pasta salad and cookie</td>
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</tr>
<tr>
<td>Back Forest Ham, Brie, and Turkey on Ciabatta Bread</td>
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<tr>
<td>Chicken Caesar salad with Fresh fruit salad, multi-grain roll, and a cookie</td>
<td></td>
</tr>
<tr>
<td>Mixed Garden Greens with Fresh fruit salad, multi-grain roll, and a cookie</td>
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**Total Selected**
Donate your car!

If you live in the United States you can donate your vehicles to the International Pemphigus & Pemphigoid Foundation! Your tax-free donation helps us continue to provide services and information to patients, their families, and caregivers around the world.

We will complete the initial paperwork for you!

Call or email us today!
(916) 922-1298
info@pemphigus.org

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Join us for our 11th Annual Patient/Doctor Meeting in Dallas, TX. Experts will be on hand to talk with patients on advances in treatments, medications, and care. Dr. Amit Pandya, UT Southwestern Medical Center, is our on-site coordinator for this year’s program and it is sizing up to be another spectacular event!