



the quarterly

WINTER 2005 • ISSUE #39

A COMMON HOPE. AN UNCOMMON BOND

LAS VEGAS MEETING HITS THE JACKPOT

International Pemphigus Foundation is a 501(c)(3) nonprofit organization. Our goals are to increase awareness of pemphigus and pemphigoid among the public and the medical community; to provide information and emotional support to pemphigus or pemphigoid patients and caregivers; to provide referrals to specialists; and to support research into advanced treatments and a cure. Founded in 1994.

Quarterly is published: Spring, Summer, Fall and Winter. The material presented in our journal is not intended as medical advice. Readers are urged to consult their physicians before making any changes in their health regimen. The opinions of contributors are not necessarily those of the International Pemphigus Foundation.

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IN THIS ISSUE

- 1 Las Vegas Meeting Recap
- 2 The View from Here
- 3 Silent Auction & Anniversary Dinner
- 5 The "Rick" of Gibraltar Story
- 6 Local Support Group News
- 8 IVIG on Fast Track
- 9 IPF Board Expands & IPF Leadership Meets
- 10 Pemphigus: A Sore Subject
- 11 Personal Fundraising Pages for the IPF

The 7th Annual Patient/Doctor Meeting opened with **Jean Barish** thanking all the participants: doctors, patients and their families, and our corporate supporters: **Peptimmune Inc., Aspreva, BioFusion, Coram, ZLBering, Accredo, and Baxter.**

Jean gave special thanks to Accredo for providing us with a facilitator for our first Support Group Leaders' Seminar.

Jean next introduced **Dr. Jean-Claude Bystryn**, Department of Dermatology, NYU, and current head of our Medical Advisory Board. Dr. Bystryn thanked meeting organizers, Jean Barish and Janet Segall, and the IPF for providing patients with this unique opportunity to hear about current information, speak with pemphigus professionals, see old friends, and make new ones. He spoke about the Foundation accomplishments and encouraged everyone to continue supporting the Foundation.

Dr. Grant Anhalt, Dept. of Dermatology, Johns Hopkins University, School of Medicine, talked about "Understanding Autoimmunity." During our last several meetings, Dr. Anhalt has delivered us a clear and concise understanding of what is meant by autoimmune disease. He discussed the components of the immune system, how it works, and why it is also very complicated and difficult to research.

He then gave us an overview of the Peptimmune study and explained exactly what their goals are and what is meant by Clinical Trials.



Ed & Hava take in some information at this years annual Patient/Doctor Meeting in Las Vegas.

Dr. David Sirois, Chairman of the Dept. of Dental Medicine at NYU Medical Center provided an overview of pemphigus and pemphigoid and explained in lay terms the disease process. He talked about the relationship between severity of disease and titer count. He believes mouth lesions must be taken as serious as body lesions. He explained his views on why there are delays in diagnosis and the best ways to get a proper diagnosis. Dr. Sirois also lead a breakout question and answer session on dental care.

Dr. Sergei Grando, Dept. of Dermatology, UC at Davis, CA, spoke to the group on treatments. He believes that there will probably be a cure within the next decade. He talked about the need for steroids; that the Nikolsy sign means that if you just push on normal skin it will cause a lesion, and told us about Dr. Nikolsy and his contribution to the clinical presentation of pemphigus. We learned about the different adjunctive therapies that are being used including his success and failure with Mestinson.

Dr. Grando believes that there is more to pemphigus than just anti-desmoglein antibodies. Hopefully, the research that is being done today

continued on page 4...



Janet Segall,
Director of
Patient Support, IPF

THE VIEW FROM HERE

A SPECIAL THANK YOU TO JEAN

Over the years, we have had many wonderful volunteers who have worked hard making the

IPF the well-respected organization it is in the pemphigus/pemphigoid community as well as in the medical and non-profit communities. One person whose contributions to the Foundation were immeasurable is Jean Barish. In 1997, I asked Jean to join our Board of Directors. Jean's qualifications to be on our Board were impeccable. She was a patent attorney for a multi-million dollar pharmaceutical company, with a Masters Degree in physiology. She has a lot of experience with non-profit organizations. She was the perfect person to become the President of our Board.

Jean's help and support over the years have meant a lot not only to the Foundation but to me as well. When I decided that the Executive Director position was not allowing me to concentrate my energies on patient support, Jean stepped up to become Interim Executive Director.

However, because of other opportunities, Jean has resigned her position, and has left the IPF. We all owe Jean a great debt of gratitude for all her efforts

over the years with many aspects of the IPF. Among her many accomplishments: she was a terrific liaison be-

tween the IPF and the various pharmaceutical companies. She was also a terrific fundraiser. She was instrumental in the development of the newsletter, the website, our annual meetings, and she put together this year's spectacular dinner program all on her own. It will be difficult to find anyone with the substance and dedication that Jean displayed on our behalf. We all wish Jean the best of luck in all her endeavors and hope that the future brings her only good things.

8th Annual Patient Doctor Meeting

Every year our meetings get better and better. This year is no different. When I left Las Vegas, I felt encouraged and excited about our next meeting. I want to thank everyone who helped me put this meeting together. It was a great effort, and a wonderful meeting and

dinner event. Next year we will have our meeting in **Washington D.C., September 23-25, 2005**. On September 23rd, we are planning a Capitol Hill Day. The IPF will make arrangements for you to visit with your Congressional representative's health advisors. We will be asking everyone who would like to participate in our Capitol Hill Day to fill out the form that will be in our next newsletter. Often we need to have several months of preparation to accomplish this goal.

Not only are we preparing for the Capitol Hill Day, but we are planning for our meeting as well. We would love to have your ideas on what you would like to see. We have received many terrific suggestions from participants from the Las Vegas meeting. If you would like to give us some suggestions, please do not hesitate to contact us at the office. ●

THE PEMPHIGUS QUARTERLY, A PUBLICATION OF THE INTERNATIONAL PEMPHIGUS FOUNDATION

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Jean Barish

FOUNDATION'S 10TH ANNIVERSARY CELEBRATED AUCTION, DINNER, AWARDS DRAW OVER 100

On October 9, 2004 the International Pemphigus Foundation celebrated its 10th Anniversary with a very special evening at the Hampton Inn Tropicana in Las Vegas, Nevada. Over 100 friends of the Foundation gathered in the main ballroom of the hotel for a silent auction, dinner and awards program, on Saturday night, Oct. 9th. It was a unique opportunity for patients, doctors and sponsors to get together and celebrate the Foundation's success over the past 10 years, and to discuss new opportunities for future growth.

Guests enjoyed cocktails, hors d'oeuvres, and good conversation as they perused the silent auction table. Items included vacation homes, collector's wine, one of a kind art work, fine linens, sports memorabilia, vases and travel coupons. A special thanks to **Robyn Youngswick Christo** for putting together the Silent Auction, and to our silent auction donors: **Charles & Elli Zimmerman, Teresa and Brian Smith, Cathey and Fred Youngswick, Bonnie and Howie Youngswick, Steven & Diane Hirsch, Barbara Isaacson, Sloan Stevens and Nancy Polster, Marlene Imbesi, Gary Roth, Ashley Youngswick, Dinesh Patel (BioFusion), and the Loa's.**

Board member **Lee Heins** served as the Master of Ceremonies for the evening program. He began the evening event with a welcome and a warm thank you to all of our sponsors, Board members, doctors and supporters. Lee thanked the many volunteers who have

worked so hard with the IPF over the years. **Jean Barish** presented **Janet Segall**, Founder and current Director of Patient Support, **Dr. Grant Anhalt**, Johns Hopkins University School of Medicine, and **Dr. Jean-Claude Bystryn**, NYU Medical Center, with Outstanding Service Awards for their dedication to making sure that patients get the best information, medical, and psychological support that they need.

As the Founder of the IPF, Janet wanted everyone to know that she would not have been able to achieve her goal without the help of so many dedicated people, especially Jean Barish, and the undaunting support of Drs. Anhalt and Bystryn. Jean has been responsible for many of the Foundation's successes both as the Board President and Interim Executive Director. From the very first day, even before the IPF obtained non-profit status, Dr. Anhalt gave his support, and Dr. Bystryn signed on soon after. Janet expressed how grateful she was for their faith in her. Janet also thanked the Board of Directors – **Sonia Tramel, Neil Kuvin, Janice Taylor, Robyn Youngswick Christo, and Lee Heins** for their dedication towards making the Foundation a success.

Upon receiving their awards, both Dr. Anhalt and Dr. Bystryn talked about how important they believe the Foundation is not only to patients, but to the medical community as well. They appealed to everyone to continue giving their support in anyway they could to make sure the IPF would always be there to do its work.

Three other awards were given this year. An award was given to both **Matt Koenig**, NY Support Group Leader, and **Dan Goodwill**, Toronto Sup-



Bystryn, Anhalt and Segall receive recognition awards.

port Group Leader for the many hours they gave toward keeping their respective support groups fresh and interesting. A final award was given to **Matt Cole**, for his contribution of graphic skills and time toward our newsletter, pamphlets, and other printed materials.

The Hampton Inn provided the IPF with a two night stay at the hotel for us to raffle off. To add to the fun, two Las Vegas Monopoly games, won by **Sloan Stevens** of Tuscon, AZ, and **Bev Siegel**, of Las Vegas were also raffled off. On Friday night 17 people went to see the 2nd City comedy group. Our contact at the Flamingo Hotel, **Mr. T.J. Hampton**, provided us with two wonderful hard covered books about the history of "2nd City". Both books were also raffled.

An amazing dessert and coffee buffet was set out and the evening concluded with a champagne toast, compliments of the Hampton Inn Tropicana. Guests mingled for some time celebrating the day's events. ●



Participants enjoy dinner and evening's events



Sloan wins Monopoly game in raffle

continued from LAS VEGAS, page 1...

will show all the possibilities for better treatments.

IVIg, Intravenous Immunoglobulin therapy, was our next presentation given by Dr. Bystryn. Dr. Bystryn has been using, and now has an on-going study on IVIg. He explained his IVIg study, as well as the studies that were done by Dr. Razzaque Ahmed in Boston. He talked



Dr. Bystryn and Dr. Sirois chat with Dr. Lebowitz during a break.

about what IVIg is, why it is being used, and how it is given. He discussed with us the benefits and the down side of using this drug – cost, and possible side effects. All in all, Dr. Bystryn believes it is effective in many patients, but not all.

We were pleased to have Dr. Anne Chang agreed to speak at our meeting about the Enbrel study that is going on at Stanford. There is research out of Europe that shows that Enbrel can possibly be a good drug for use in pemphigus. Enbrel is an approved drug in the U.S. for Rheumatoid Arthritis, but it is being used off-label for pemphigus. She explained the double blind study that Stanford is doing, and wanted to let everyone know that if they are interested in being a part of the study, to contact her. Call to ask for more information (656-724-0881) or email Skinstudies@yahoo.com (more information on the Enbrel study is on the IPF website.)

Dr. Anhalt gave us an overview of another new drug being used in the treatment of pemphigus – Rituxamab. He explained that Rituxamab is what is called a monoclonal antibody. It was genetically engineered for the treatment of Non-Hodgkins lymphoma. He explained how

Rituxamab works and why it is considered a benign drug. He explained how it is given, and the cost; which is expensive but not as expensive as IVIg. Although there are impressive reports, it is now used more for patients with PNP. There is potential for its use with more and more patients with pemphigus vulgaris.

At the end of our morning sessions, we broke up into several different groups. **Neil Kuvin**, whose son has PV, led a group of caregivers. The “care-givers” breakout session provided for a very animated discussion of the role that parents, spouses, brothers, sisters and even friends play in the daily life of a patient. The most repeated elements mentioned

for a care-giver were patience, understanding, and an atmosphere of hope – hope being considered the most essential. The definitive link between the nervous system and the immune system was the subject of some conversation, leading to the proposition that peace of mind and reduced stress can and does have a positive impact on the diseases. Other things mentioned included assisting with medication, an attitude of listening and little things like providing transportation.

Janet Segall and Sonia Tramel led a discussion on lifestyle issues. Topics discussed were: how to address or ignore questions and looks from others, educating others, the humpback, puffy face, emotional feelings, sun exposure, and bandages.

Matt Koenig led a group on starting a support group, and Jean Barish was available to answer any questions regarding the Foundation.

After the lunch break the first presentation was given by Dr. Anhalt on the best way to manage the side effects of

drugs. He talked extensively about prednisone, its side effects and some of the ways to best treat these side effects.

He discussed some of the side effects of prednisone, how best to manage weight, how to deal with osteoporosis by following the guidelines set out by the College of Rheumatology. He made us aware that infections can occur when someone is immunosuppressed. Risk factors can be related to age, other underlying medical conditions, and the degree you are immunosuppressed. All patients should get the flu vaccine as well as all members of someone’s family. Pneumonia shots are also recommended. Wash your hands and your face several times a day.

For the pain of skin lesions Dr. Anhalt says the best way is to make sure the lesions are healed and the only way to heal the lesions is by taking the drugs. The only topical that might work for the pain of open lesions for wound care is Xerofoam gauze, a petrolatum gauze dressing. If someone has PF or BP, and just a few lesions, then inter-lesional injections and topicals can actually provide some benefit.

He talked about blood pressure medicines, commenting that doctors recommend not taking the Ace-Inhibitor.



Angela, Richard and Peter take a break during the meeting.

Topical anti-fungal drugs can be used for yeast infection.

The next speaker was **Dr. Animesh Sinha** who is a Dermatologist and researcher at Cornell University Medical Center in New York. Dr. Sinha is doing

continued on page 7...

REMOTE LOCATIONS PRESENT ADDITIONAL CHALLENGES TO PROPER DIAGNOSIS

“RICK” OF GILBRALTAR SHARES HIS PV STORY

by *Richard J Labrador*

Taking the lead from Anna Lisa Riccardi in Italy, I too would like to share my experience with the readers, however, this time coming from Gibraltar.

Gibraltar is a (very) small British territory at the South tip of Europe with 30,000 population. Technically a British colony, it enjoys a very large degree of self-government and is very proud to be British – this year it is celebration 300 years of British rule for it was captured from Spain back in 1704. The territory of Gibraltar is linked to Spain by a small isthmus and Spain continues to harass Gibraltar in every possible way in an effort to recover its sovereignty – Spain will never succeed!

Back in November 2002 I was working as a volunteer marshal at the European Volvo Masters golf competition at Valderrama (south of Spain where the first Ryder Cup was played in Europe outside the UK). For a couple of days I felt as if I had a small fish bone in my throat, on the Monday following the weekend competition I felt unwell and visited the local Primary Care Centre and was seen to by a young doctor. She thought I had developed a throat infection – this was what it looked like – and prescribed me antibiotics and asked me to return in seven days time if it had not cleared. It did not so I went back and she referred me to the Centre’s dental surgeon; I could not understand why she had done this. When the dental surgeon saw me he was not sure what it might have been and asked me to return in two weeks time in order to see how the ‘infection’ was developing. By the time I returned what appeared to have been a throat infection had gone and was replaced by occasional blisters in the mouth. The dental surgeon, in his early 40s, immediately suspected what it was and carried out a biopsy which was sent to a laboratory in the

UK. I quote his age because like with the Italian example, a senior (57 year old) dentist friend of mine and very well respected both in Gibraltar and nearby Spain as a very competent professional, had no idea what my condition could have been. Clearly, at least in this part of the world, Europe Mediterranean region, older dentists do not seem to be familiar with PV.

Once we had a positive diagnosis I had to start treatment immediately. Gibraltar, because of the size of its population, does not have a resident dermatologist, however, there is a visiting dermatologist from nearby Spain who comes into the Centre one day per month, and there are two UK visiting consultant dermatologists who take it in turn to visit Gibraltar once every two months. I was first seen by the Spanish dermatologist who is now managing my condition. He started me off with 90mg Calcort (Deflazacort) per day and I am now down 6mg per day. I am also seen by the UK visiting consultant dermatologists who keep an eye on me. All treatment is paid for by the Government of Gibraltar Health Authority – health care in Gibraltar is, very much like in the

UK, available through the state at no cost to the patient. I am the only PV sufferer in Gibraltar – not surprising with only 30,000 population.

I am a 57 years old safety consultant married to Clarissa and have three daughters all single: Tessa 24 Accountant, Anna 23 International Business, and Emma 20 reading 2nd year Law. Although I have a technical background, telecommunications, I have for the past twenty years concentrated on occupational safety and health. I worked for the British Ministry of Defence in Gibraltar for 33 years and took voluntary redundancy in 2000. I am now self-employed and my two main functions are my safety consultancy and also my personal injury claims management company which I run. I call it the ‘before and after.’ With my safety consultancy I make sure people do not suffer accidents at work, however, should someone suffer an accident involving personal injury they can come to me as claims manager and I will attempt to obtain compensation! In my spare time I play golf and avoid alcohol, spicy food and above all hot (warn) food or drink which is what mainly triggers off the blisters. ●



Richard Labrador and family

ATLANTA, DALLAS, NEW YORK, LOS ANGELES

LOCAL SUPPORT GROUP NEWS

Atlanta Support Group

The Atlanta Support Group held its first meeting on August 28, 2004 at Emory University's Medical Clinic. The guest speaker was Dr. Robert Swerlick. As the only experts in the Atlanta area, he probably sees the majority of pemphigus and pemphigoid cases. Dr. Swerlick talked about the diseases and answered questions from patients. He feels that a support group or network is a very positive first step for patients in the area.

Janet Segall, Director of Patient Support for the IPF, joined Dr. Swerlick at this first support group meeting. She also emphasized how important she felt it was for patients to help one another with the issues that might come up with each person's individual disease process. She mentioned that if it were inconvenient for people to meet on a regular basis, a phone support network can work wonders as well. A meeting could then be set up for everyone to meet, once or twice a year.

If you are interested in getting in touch with someone in the Atlanta area, contact Cecilia Espinosa Murphy – 770-532-1636. Cecilia is also fluent in Spanish. ●

Dallas Support Group

The Dallas, Texas, IPF Support Group met on November 16, at 6:30 pm. Thirteen people were in attendance. Angela Vickers, president, began the meeting by welcoming everyone, especially several new families who were attending our group meeting for the first time. Angela gave an excellent overview of the annual meeting that took place in Las Vegas.

We were pleased to have Dr. Amit Pandya join us to review a list of questions members had discussed at the annual meeting. It was a big help for those who were not able to attend. Dr. Pandya reviewed the questions and helped us better understand what had been discussed at the annual meeting. Then he opened up the meeting for questions from our group. Several visitors and caregivers had concerns which he was able to address.

After the questions and answers, we enjoyed a social time where we were able to get to know the new visitors to our group. Joyce Korn, our Dallas Heart 2 Heart volunteer, served a wonderful buffet. Angela invited everyone to join the IPF and begin getting the newsletter. Karen Tellez, the Fort Worth Heart 2 Heart volunteer, encouraged those new to our group to sign up for the email discussion group and to join the on-line chat group. ●

New York Support Group

On September 12th, the NY support group warmly received a visit from Janet Segall, IPF Founder and currently Director of Patient Support. About 25 of us, many recently diagnosed, listened as Janet recounted her own history and that of the IPF. This was followed by a full range of questions covering the organization's activities and plans. We adjourned for lunch at Notaro's as the conversation turned to the upcoming Las Vegas conference and beyond. Janet offered plenty of great advice and encouragement, and the group returned that encouragement by turning the lunch into an impromptu fund raiser for the conference. The NY group offers their congratulations to Janet and the IPF for ten years of reaching out to the Pemphigus community, the doctors, researchers, health professionals and families, and for bringing them together in so many ways to support us. ●

Los Angeles Support Group

A barbeque was held at the home of Sonia Tramel in Long Beach, CA on Saturday Sept 11, 2004. Roy DeViso was our head chef. He did an outstanding job. Twenty people attended the event, eight of whom we met for the first time.

We watched the IPF video which gives a presentation of a young boy with pemphigus and introduces some of the supporting doctors and members. We held a question and answer period and Barbara Roller gave an excellent presentation of her participation in the Peptimmune's Clinical Trial. ●

IPF LOCAL SUPPORT GROUPS

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Email: alz46@yahoo.it
www.idi.it/amb/csmba/index.htm

Philippines - Dr. Benjamin Bince
Jose Reyes Memorial Medical Center
(632) 711-6740; Email: bbin@runbox.com

Online/Website
www.pemphigus.org/support.html
www.pemphigus.org
webmaster@pemphigus.org

In the UK, the PV Network is a patient support group providing information and support for people living with pemphigus, their families and caregivers.

The PV Network - Siri Lowe, Exec. Director
For information and support - 020-8690-6462
or send a self-addressed, stamped envelope to:

Flat C, 26 St. Germans Rd., SE23 1RJ
www.pemphigus.org.uk

continued from LAS VEGAS, page 4...

research on the Role of T-Lymphocytes (lymphocytes are white blood cells) in pemphigus vulgaris. The question he is trying to answer is: How do these cells mastermind and control the split that happens in the skin? He also feels that in the next decade, as technology improves, there is hope that there will be better treatments available.

Last session of the day was Matt Koenig, Leader of the NY Support Group, and **Barbara Roller**, Los Angeles Support Group talking about their experiences with Phase I of Peptimmune's Clinical Trial. Matt is the first participant in Peptimmune's Clinical Study.

He decided to participate in the study based on his confidence of **Dr. Jim Rasmussen** from Peptimmune, and Dr. Strober who is the NY Clinical Trial site.

He wanted to recommend that people be a part of the study, but felt that he couldn't recommend it unless he was willing to do it himself. He asked himself, "How often does one get to do something new for the first time, or be a part of something bigger than ourselves?" He thought this was a great opportunity.

So far there have been 15 people in the trial. There have been no bad reactions from the infusions. It was anti-climatic. His symptoms did not get better, nor did they get worse. He called on anyone in or near the cities sites of the trial to please volunteer.

Barbara Roller also spoke about her participation in the clinical trial. She was convinced to take part when the Foundation sent out letters to everyone encouraging all who could to volunteer. Barbara felt like she was on a mission. She received a larger dose than Matt but nothing

bad happened. This is Phase I and they are testing for the product's safety. As they go to Phase II more people will be needed. Barbara assured everyone that she will give updates, and urge all who can to you to participate. She believes it will make a difference and we will never know if it is going to work unless we try.

Everyone talked about how impressed they were with the speakers. We closed the meeting and sent everyone back to their homes or rooms to relax and get ready for the evening's events.

We opened up Sunday's meeting with **Shelley Diamond, M.A.** in Psychology who talked to the group about the

role of stress in autoimmune diseases, and the different ways in which stress can affect all aspects of one's life. She talked of her own experience with a skin disease.

After Ms. Diamond's presentation, we had our patient panel with three people of different ages, and in different stages of their recovery. The whole group participated in the discussions.

The meeting ended at noon, but for those who were interested, we a representative join us from CoverBlend by Exuviance Makeovers to give make-up tips and make-overs to anyone who wanted to stay. The meeting was a huge success. ●

Heart ♡ Heart

Alabama -----	New York ... Linda Tafet (June-Sept) ... 845-425-4917 ... lin2124@aol.com
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Kirsten R Bellur

AN HMO PERSPECTIVE ON PUTTING IVIG ON THE FAST-TRACK

Whether it is from a PPO or HMO plan, there is, unfortunately, no single path to follow

to achieve a streamlined, simplified, and expeditious approach to obtain IVIG – on a “fast-track” that would work for everyone. While one wishes it was possible to reduce the process to a few simple steps, one can still navigate what must be done. I’ll attempt to highlight some of the more important steps I have taken in dealing with my HMO plan to obtain this treatment for PF.

As a general rule, it is important to document everything, keep copies of all medical records, lab tests, and read medical articles pertaining to Pemphigus. I have also found it very useful to develop a written table listing my drug schedule/tapering, for easy reference. That way I have over 6 years of valuable information concentrated on just one page, very easy to understand and use.

Key Points:

- 1) **Educate yourself in order to present your case professionally to your health plan.**
- 2) **Interact with your plan in writing so you have a record.**
- 3) **Address correspondence to the top administrator within your plan.**
- 4) **Confirm all phone conversations with your plan in writing. List what was verbally agreed upon in writing, so you are prepared to deal with new people within the system.**
- 5) **If you go through grievance procedures, request copies from your plan – you may be surprised to find out who makes the decision and on what it is based.**

Bear in mind the ultimate responsibility is with you, the patient, to deal with

your health plan. Use the points stated above – a written approach and all your acquired knowledge and skills – to tackle the task of dealing with your health plan. You are up against corporations that have a large complex bureaucracy and very clever accountants and lawyers well skilled in the matrix management. My point here is not to criticize or indict, but to be pragmatic – this is a business, and you have to treat it like a business: professionally.

I think that it is where so many patients fail or give up when faced with adversity. I’d guess that if health plans said “yes” to everyone the first time, they’d go under. So it has seemed to me that they necessarily have road blocks to deal with that. I have learned to accept these road blocks, and look at them as just something to get around. One must be tenacious.

That said, belligerent attitudes are not necessarily called for. Preferable is the “kill them with kindness” approach. It is important for us to understand that health insurance providers seldom have guidelines to follow when it comes to rare diseases, so they will usually decline your request at first. It is then up to you to convince them that your treatment is vital and that it would also most likely be beneficial to them in the long run if they approve your proposed drug/treatment, because if you are in a long-term durable clinical remission, they will save money – always remember, they are businesses, and it comes down to a bottom-line issue, fair or not.

The next important point is that you should try to find a team of experts/specialists who you. (for HMO plans, some of them will most likely be outside the plan providers). This might be the most important point so I’ll elaborate and share my personal experience.

I could never have achieved my goal of getting IVIG treatment approved and administered at my local HMO if it was not for the cooperation, support

and guidance I received from an expert outside provider, M. Peter Marinkovich, M.D. at Stanford University. Dr. Marinkovich specified my treatment course, wrote the protocol for administering the treatment, and he was always available for consultation during the 7 months of therapy. It’s important to understand that many patients in smaller communities deal with HMO/PPO plans who don’t have physicians on staff or on preferred provider lists qualified to handle the treatment of rarer diseases – it’s not cost effective for them. Therefore, as in my case, the prescription/protocol for IVIG came from an outside provider, but the therapy could be administered within the plan. The result was a compromise that worked.

After completing the IV treatment, I decided to prepare and forward a proposed simplified, expeditious, and streamlined – a “Fast-Track” – approach for IVIG to be followed in the future. The proposal has now been accepted by my local HMO plan as standard procedure for Pemphigus patient. It gives me peace of mind to know that other patients needing the treatment in the future will not have to go through the difficulty I did.

I’ve met some people at the IPF annual meetings who accepted their “fate” too easily and settled for inferior drugs and/or treatments from their health insurance plans, because they took “NO” for an answer. I hope by briefly highlighting the most important aspects of my struggle to obtain IVIG treatment that I may in a small way help or embolden other patients in the same situation to take on their health insurance plan.

This is not an easy task. It can become a continuing crusade to get more expensive drugs and treatments approved. Therefore, I believe it is important to be determined, perseverant, and undaunted by set-backs. After all, the quality and quantity of your life is worth it! ●

IPF WELCOMES DRs. KORMAN & PANDYA

ADVISORY BOARD EXPANDS

Neil J. Korman, M.D., Ph.D

Neil Korman obtained a Ph.D. in biomedical engineering in 1982, studying the tissue response to implants, and his M.D. in 1984 both from Case Western Reserve University. After his clinical residency in dermatology at University Hospitals of Cleveland, he pursued fellowship training in immunodermatology at the Dermatology Branch of the National Cancer Institute of the NIH. While Dr. Korman was at the NIH he was very fortunate to be trained by another Medical Advisory Board Member, Dr. John Stanley and to also work with Dr Masayuki Amagai, another Medical Advisory Board Member. After completing his training at the NIH, Dr. Korman joined the faculty in the Department of Dermatology at Case

Western Reserve University in 1990. Dr. Korman is the Director of the Immunobullous Disease Program and of Clinical Trials at Case Western Reserve and is very involved in the Peptimmune Phase I Clinical Trial to treat pemphigus vulgaris. ●



Amit G. Pandya M.D.

Dr. Amit G. Pandya is a Professor in the Department of Dermatology at the University of Texas Southwestern Medical Center in Dallas, Texas. He serves as Director of the Clinical Studies Section in the Department of Dermatology and Director of the Clinic for Cutaneous Lymphoproliferative Disorders. He earned his Doctor of Medicine degree from UT Southwestern Medical School and com-

pleted residencies in Internal Medicine at Presbyterian Hospital of Dallas and in Dermatology at UT Southwestern Medical Center. Dr. Pandya has a special clinical interest in pigmentary disorders, autoimmune blistering skin disorders, cutaneous lymphomas and the dermatologic manifestations of systemic diseases. His ongoing clinical research studies are in the diagnosis and treatment of these cutaneous disorders. ●

SUPPORT GROUP LEADERS HUDDLE DURING LAS VEGAS MEETING

IPF HOLDS FIRST LEADERSHIP CONFERENCE

by Matt Koenig

This year's IPF conference at Las Vegas had an added bonus – the first meeting to bring together the leaders of the various regional support groups along with the leadership of the IPF. This was a wonderful opportunity for us to get acquainted, compare notes regarding the challenges of running a group, and recount the success stories that we have experienced. Many of us were meeting each other for the first time, and I was delighted to meet everyone. We even had Alan Papert from Boston participating via conference phone!

We began with a presentation from Dee Robertson from Accredo Corporation. Dee put together a checklist of all the actions and responsibilities that are necessary for creating and maintaining a support group. Besides lending time and material support to the IPF, Dee and

her company have many contacts in the autoimmune community. Dee has relayed her company's interest in supporting to all of the regional support groups and any new groups that will be established.



The group then received the treat of hearing me speak about the New York experience, Pemphigus style! We focused on the importance of establishing a mission statement, not so much for others to read but for keeping focus on our responsibilities and goals. This includes education, interaction, communication, and referral. These factors are critical in maintaining a viable and long lasting support group. We've also benefited from

7 initial years of leadership from Joan DeLucie, who founded the NY support group in 1995. The NY meetings follow a general plan of presentation, discussion, and food.

But group leadership represents more than holding meetings. The leadership group went on to discuss many pertinent topics, such as getting and keeping members involved, supporting those who are unable to attend meetings, reaching out to the medical community, and just keeping everything moving along. For all of our groups, the most important resource is our membership. We recognized that our leadership responsibility is to motivate members to participate and give from their strengths, in order to help all of us improve our health and well-being. That's why we agreed to form a stronger national network amongst ourselves, as well as continue to reach out to our members and communities. ●

RESEARCH MAY HAVE APPLICATIONS TO OTHER AUTOIMMUNE DISEASES

PEMPHIGUS: A SORE SUBJECT*Introduction by Dorothy Weinberg*

The Pioneer Press, a weekly publication owned by the Chicago Sun Times, published the following article about pemphigus and pemphigoid in the newspaper's Health section on October 21, 2004. The reporter who wrote the article, Stephanie Fosnight, interviewed Dorothy Weinberg, who lives in Glenview, IL a suburb of Chicago. A photographer also came to Dorothy's home and took her photo for the article. Dorothy told of her experience as a pemphigus sufferer since 1999 and how she has gone through five doctors and two dentists before being treated by Dr. Michael Tharp, Professor and Chairman of Rush Medical Center in Chicago and by Dr. Joseph Silberman, a dentist in Evanston, IL. Since she has seen these medical practitioners, her symptoms have been greatly alleviated.

The article also included interviews with other people and their families who have experienced pemphigus. The writer also interviewed Dr. Jean-Claude Bystry, a physician and researcher at the New York University School of Medicine, and Tom Mathers, president of Peptimmune, which has developed a pemphigus treatment.

**by Stephanie Fosnight, Staff Writer,
Pioneer Press**

Dorothy Weinberg of Glenview was diagnosed with pemphigus vulgaris in 1999. At first she didn't want to talk about the rare disease, but now she's on a mission to get the word out. (Julie Fabiszak/Staff Photographer)

Imagine a disease that causes the skin to literally become unglued. Imagine a young man whose face unpredictably breaks out in sores so raw that it looks like he was dragged over a bed of razor blades.

Imagine a woman who worked hard to prepare her family's Rosh Hashana feast and then had to sit idly by as her relatives dug in, because the sores in her mouth made it too painful for her to swallow.

Now work the name of this rare disease into your vocabulary: pemphigus vulgaris.

"Pemphigus vulgaris," said pemphigus sufferer Barbara Roller, sounding slightly repulsed. "What a wonderful name."

For the approximately 10,000 people in the United States with pemphigus vulgaris and other forms of pemphigus, the scenarios detailed above are a way of life. So is patiently explaining the little-known condition, which can affect anybody but seems to concentrate more heavily in certain populations, like Jews of Eastern European descent.

People with pemphigus also have to learn to live with daily doses of steroids and autoimmune suppressants to help keep their condition under control, and at the same time live with major side effects of both drugs. Yet new research offers hope not only for pemphigus patients, but also for sufferers of other rare autoimmune diseases.

"Autoimmune diseases have a very significant impact on the population, and understanding one will lead us to understand the others better," said Jean-Claude Bystry, a physician and researcher at the New York University School of Medicine. Bystry pointed out that, as a group, autoimmune disease is one of the biggest killers in America.

Pemphigus occurs when the body mistakenly attacks a vital protein, desmoglein, which literally glues together cells in the skin and mucous membranes. When the body's autoantibodies attack the desmoglein, skin cells become separated and the skin can peel up into burn-like lesions or blisters that do not heal.

"The skin just falls off all over," said Roller of Agoura Hills, California, who was diagnosed with pemphigus vulgaris nine-and-a-half years ago. "It's very painful."

Dorothy Weinberg of Glenview first noticed a sore on her chest that didn't go away in 1999, and then she started feeling sores in her mouth and on her gums. Doctors initially told her she had a virus, but when the sores remained, an oral surgeon finally suggested she have a biopsy to confirm pemphigus.



Julie Fabiszak/Pioneer Press Staff Photographer

Dorothy Weinberg was diagnosed with PV in 1999. At first she didn't want to talk about it, but now she's on a mission to get the word out.

By Rosh Hashana of that year, Weinberg was in considerable pain.

"I could not swallow comfortably," she said. "I remember distinctly sitting at this table with all these people and all of this food I had prepared, and I couldn't eat hardly anything."

Next came red sores on her head.

"I thought I was going to go nuts. They itched!" she said. "It was almost like a magnet. I'd be sitting there and my hands would go up to my head."

Weinberg got topical shots to help control the sores on her head. So did Roller, although the medications she used were so strong that her hair fell out.

"It was horrendous," she said. "I was really bald for about a year."

Roller also had sores down her throat, on her face, on her eyelids, around her ears, and on her chest and back. And still, she said, hers was only a moderate case.

Weinberg, who said her own pemphigus is minor, recently found a sore on her toes. But, she says, her story is one of the least tragic.

"Undiagnosed and untreated, pemphigus can be fatal," said Neil Kuvin,

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a Louisville public relations specialist whose 24-year-old son has suffered from pemphigus since the age of 16. "It eats away flesh and tissue. The percentages of (fatal cases) are not infinitesimal. Treated patients are still facing a potential five to ten percent fatality rate."

Kuvin's son is the young man whose face can look like it was scraped by razors.

"He can go for months with little noticeable lesions," Kuvin said. "Then, all of a sudden, we're not sure why, it will break out. Then it will clear up again. There's no rhyme or reason."

Kuvin, Roller and Weinberg all listed the dangerous side effects of the common treatments for pemphigus -- steroids and autoimmune suppressants.

"Pemphigus used to be considered a disease you got after you were 50 or 60 years old," Kuvin said. "Now there are kids 3 years old. Think of a life on prednisone. It won't last long. Your life is going to be cut short, if not by the disease, then by the effects of the prednisone."

Prednisone, the most commonly-diagnosed steroid, is an anti-inflammatory that helps keep the blisters down and also helps suppress the patient's immune system that recognizes the crucial protein desmoglein as foreign.

Roller recited a litany of steroid side effects which include osteoporosis, cataracts, weight gain, fungal infections, yeast infections and susceptibility to bruising.

"I have very thin skin and it tears off easily, so I have to be very careful I don't get wounded. A little scrape can turn into a terrible infection," she said.

Roller, a self-described optimist about pemphigus, emphasized over and over that there's an antidote for every side effect. Still, she was eager to volunteer for the safety trial of a new treatment developed by the Cambridge, Mass. drug company Peptimmune.

"You meet these patients with rare disease and they're so desperate for anything," said Tom Mathers, president of Peptimmune, which has developed a pemphigus treatment similar to allergy shots. "There's really not been any good treatment solutions for them and they're taking these massive doses of steroids which have deleterious effects."

Roller enthusiastically reports no adverse side effects during the first phase of the trial, when she was given small injections of the pemphigus-causing antigens.

"We're trying to tolerize the patients," Mathers said. "Next stage, we'll go for broke. We'll give them the peptide and then begin to withdraw their steroids. I cross my fingers every day that this clinical trial gives us a sign to charge full speed ahead."

Pemphigus is an ideal autoimmune disease for research because all of the abnormalities have been identified, said Dr. Bystryn of NYU's medical school.

"In pemphigus, the reaction is directed to two different targets," he said. "In other cases the target has not been identified, like in diabetes."

Bystryn is developing another pemphigus treatment called intravenous immunoglobulin, or IVIG. In this treatment, researchers stimulate the body to reduce the number of antibodies in the body, good and bad. Then they give the patient the IVIG preparation, which contains replacement antibodies, except for the "bad" antibody that causes pemphigus.

"The end result is you're degrading everything and you replace what is good and not what is bad," Bystryn said. His results also may have implications for studying other rare autoimmune diseases.

"If you find a way of treating one disease, then maybe you can find a way of treating the other disease in the same way," he said.

Roller can't wait for the conclusion of the Peptimmune study. If all goes well, Mather said, the treatment should be available by 2007, signaling a new era for pemphigus patients, and hopefully laying the groundwork for similar treatment of other autoimmune diseases.

"I know it's going to work, I just feel it in my guts," Roller enthused. "This is going to be a breakthrough for autoimmunity." ●

Stephanie Fosnight can be reached at sfosnight@pioneerlocal.com

Our thanks to the following companies for their generous support at the recent Patient/Doctor Meeting in Las Vegas:



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