5th Annual Event Strikes a Chord

The Fifth Annual International Pemphigus Foundation Patient/Doctor Meeting was held on August 3, 2002, at New York University Medical Center in New York. Patients from all over the country came to hear medical experts discuss pemphigus and pemphigoid. Additionally, a panel of patients shared their personal experiences of living with pemphigus. Executive Director, Janet Segall and IPF Board President, Jean Barish spoke to the group. The program was followed by a cocktail party and dinner at the New York Helmsley Hotel. Our thanks to Caram Healthcare and Aventis Behring for their generous support. Thanks, too, to the New York Helmsley Hotel for their assistance and support.

Dr. Grant Anhalt, Department of Dermatology, Johns Hopkins Medical Center, opened the morning session by talking about the immune system and autoimmunity. The immune system is very complex. A number of different organs comprise the immune system — the bone marrow, the lymph nodes and the spleen. These organs have the same function — to produce antibodies that protect the body from invading organisms such as bacteria, viruses and parasites.

Another characteristic of the immune system is that an individual's genetic makeup plays a role in the immune response, making each individual's immune system unique. When a person has an autoimmune disease such as pemphigus, the body has developed an immune response to itself. This is called "autoimmunity." Autoimmunity, therefore, is an aberration of the normal immune response. In pemphigus/pemphigoid, the aberration of the immune response involves the development of auto-antibodies to specific proteins called desmogleins that attach skin cells together.

Our second speaker was Dr. Jean-Claude Bystryn, Department of Dermatology, New York University Medical Center. Dr. Bystryn discussed treatments for pemphigus, particularly intravenous immunoglobulin, IVIg. He explained that the medical community knows that steroids (prednisone) are the class of drugs that work best for pemphigus, and that with the use of steroids the mortality rate of pemphigus has decreased significantly. However, steroids have numerous undesirable side-effects, and adjunctive drugs, including immunosuppressants and IVIg, can be used as "steroid sparing" drugs. Immunosuppressants reduce the activity of the immune system, whereas IVIg has a different mechanism of action which is still to be determined. For maximum efficacy it is best to combine IVIg and immunosuppressants.

IVIg seems to be most helpful when a patient has resistant pemphigus, and other therapies do not control the disease. Research on the use of IVIg to treat autoimmune diseases is limited. Preliminary evidence, however, suggests that IVIg is effective in the treatment of pemphigus and pemphigoid. Unfortunately there is no standard protocol for IVIg administration in pemphigus and pemphigoid patients. While the amount given in one dose has been standardized, the frequency of dosing varies depending on the individual response to the drug.

Our next presenter was Dr. David Sirois, Professor & Chairmain, Department of Oral Medicine, NYU College of Dentistry. Dr. Sirois explained that it is important that dentists be sympathetic, and understand the complications that can occur due to pemphigus and pemphigoid. It is not uncommon for people with gum disease due to pemphigus to resist taking...
THE VIEW FROM HERE

The Value of Continuing Support

The following is my presentation at this year's Annual Meeting in New York. I realize that I have talked many times about how important it is for us to seek support and give support, but I believe that when we help others, we help ourselves heal as well.

Now that we have formally become International, I ask everyone to do what you can to help others. We would love to have stories from people living with pemphigus/pemphigoid in other countries. We would like to know about how your country deals with a disease like pemphigus.

"A year ago, New York City and this country experienced a terrible trauma. One day we were going about our business, and the next day our lives took on a new perspective, and our country changed.

Last week, I received a letter from a member of our community who lost her son on Sept. 11th. He was a fireman for the New York Fire Dept. I would just like to say, to her and to all of you who lost someone you knew or loved, my thoughts and prayers go out to you and your families.

One of the ways I was able to deal with the events of September 11 was to turn to my family and friends. We were all on the phone to each other for days on end, and we still talk about it frequently. I believe the best way to get through bad times in our lives is with support from one another.

I have been living with pemphigus vulgaris now for almost 20 years, but I still remember that sinking feeling I had when I was diagnosed. I was in shock. I was 37 years old and raising a 6 year-old by myself. I thought I was a dead person and my daughter was going to be an orphan (as her father had died some years before). I was devastated. I'm sure many of you understand these feelings.

I felt very alone, as it was difficult for my family and friends to understand how I was feeling. They couldn't relate very well to this particular issue. After two substantial remissions, my disease reappeared. That was when I decided to try and start a Foundation. I wanted to find others who knew how I was feeling, and I did. I couldn't have met a more wonderful group of men and women (and some children) who helped me to look at my disease in a different way. Over the years, each and every person I have met and spoken to renew my life and my hope. That is what you have done for me.

Helping one another is also why I think support groups are so important. One of the reasons why the New York support group and the Toronto support group have been so successful is that the more seasoned members have stayed to help support the newly diagnosed – to help them learn how to understand, live and deal with their disease in the best possible way they can. I get contacted almost every day – sometimes 3 or 4 times in a day – from someone who is just diagnosed or knows someone who is just diagnosed. If they live in New York, Toronto, or Los Angeles, I suggest that they contact the respective group leaders and join a meeting. For those of you who have been living with pemphigus for a while now: you can help others so much. For those of you who are newly diagnosed – ask for support. It can really make a difference. And, of course, the Foundation needs your continued support so we can keep putting all of you together and so that hope stays eternal that we will find other reasons to know one another and stay connected.”

Susan Hope Maizner, age 63, passed away peacefully at home August 8, 2002, at Cave Creek, AZ after her courageous battle with cancer.

The Foundation and email discussion group have lost a great friend and supporter, and we have all lost a valuable member of our community.

Susan was the founder of "Pemphigus and You" online support forum, through which, (as well as through Foundation channels), she provided many of us with information, encouragement, and support. She will be deeply missed.

Susan Hope Maizner
Executive Director, NPF

International Pemphigus Foundation

"A common hope, an uncommon bond"

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.

BOARD OF DIRECTORS
President: Joan B. Bank, Esq.
Vice President: In Charge of Scientific Affairs / Grant Anhalt, M.D.
Vice President: The Honorable Janie A. Taylor
Secretary: Lee Means
Treasurer: Carol Faubel

EXECUTIVE DIRECTOR: Susan Hope Maizner

HEADQUARTERS:
212 11th Street, Suite 100, San Francisco, California 94103
Phone: 510-527-8457  Fax: 510-527-8457
Email: prnews@npi.com Website: http://www.pemphigus.org
Mail Address: P.O. Box 5606 Berkeley, CA 94709-0506
Quarterly is published: Spring/February 15, Summer/May 15, Fall/August 15 and Winter/November 15. 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.

© Copyright 2002, International Pemphigus Foundation. All Rights Reserved.
Pemphigus and Courage Go Hand in Hand

The recent IPF doctor/patient meeting in New York was a great success. Despite brutally hot weather, many of you came for an opportunity to learn more about pemphigus and pemphigoid, and to meet and socialize. We thank everyone who worked so hard to make this meeting so terrific.

While it is difficult to single out any one presentation, the most special part of the meeting for me was a panel presentation by pemphigus sufferers who spoke about their personal experiences with this difficult disease. Each person told a story of delayed diagnosis, fear and uncertainty, pain, and unpleasant drug therapies. The stories were riveting... and heartbreaking. There were accounts of layers of skin peeling off, time spent in a burn unit, and months of going from doctor to doctor before there was a correct diagnosis.

But in addition to hearing these difficulties, I was struck even more by something else. What I saw in each of the panelists was a great deal of courage. This was something new to me. I have met many of you over the years. At each annual meeting I have come away learning more. I have seen optimism, energy, and determination. But the raw gutsiness I saw at this meeting was a revelation. And an inspiration.

I don't believe I ever realized before just how difficult it is to live with pemphigus. When Robyn calmly talked about huge blisters on her scalp, or when Sloan described how she was temporarily disfigured, I found myself wondering how I would react if that had been me. When Terry spoke about visiting over a dozen doctors before getting a diagnosis I wondered if I would have had what it took to be so persistent. When everyone so matter-of-factly discussed the ravages of pemphigus, without complaining and expressing any self-pity, I felt I could never be so brave in the face of so much adversity. The personal stories in this issue of the Quarterly are further examples of this courage.

This courage that you have is not only inspiring, it can also be very helpful to you and others. It can help give you the strength you need to continue to live successful, productive, satisfying lives. It can also help show others with pemphigus/pemphigoid, especially those recently diagnosed, how to best overcome the adversity of these diseases. And it can inspire the medical and scientific communities to seek better treatments and a cure.

You are all doing so very well. With your courage and determination you will continue to do even better.

IPF Medical Advisory Board Member Recognized as One of New York's Best

by Robyn Youngwick

Recently, New York Magazine did a cover story on the best doctors in the city. At last count, New York had over 60,000 doctors in the City, the highest concentration in the country (Kaufman 2002). Being listed in this small group of 1,500 is looked upon as a highly prestigious recognition.

Patients are constantly faced with the task of finding a good doctor among a sea of thousands. We go on recommendations from friends, family and acquaintances. Once we do find a good doctor, we become quite possibly, one of the greatest advertisers for their practice. So, when a prestigious magazine lists a doctor as one of the best, 1,500 out of that sea of thousands, and makes it just a little bit easier for patients to find them, that physician is obviously first-rate.

Dr. Jean-Claude Bystryn, a member of the IPF's Medical Advisory Board since its inception, was among thirty-two Dermatologists in New York to be listed in the issue. Dr. Bystryn was the only Dermatologist listed as specializing in blistering diseases such as pemphigus.

In addition to Dr. Bystryn, Dr. Seth Orlow was also recognized as one of the 1,500 best of New York. Dr. Orlow specializes in Pediatric Dermatology, which includes pediatric pemphigus. He has been very helpful to several members of our community.

Dr. Bystryn says that he is "pleased to be included among the physicians that this publication feeds are among the best." He has been studying pemphigus for almost thirty years. He is credited with setting up one of the first labs in the country that could measure abnormal antibodies that are present in patients with blistering diseases.

Currently, Dr. Bystryn is working on several research projects on pemphigus. He is evaluating the use of IVIg (Intravenous Immunoglobulin) for the treatment of the disease, as well as studying the mechanisms of how this treatment actually works. Dr. Bystryn is also studying the clinical outcome of a large number of patients with the disease that he has treated over the years. He says that, "in doing this, we can hopefully gain a better understanding of how quickly patients respond to therapy in general."

Dr. Bystryn was born in Paris, France but has since become a U.S. citizen. He received his B.S. in Biochemistry from the University of Chicago and went on to receive his M.D. from NYU. Dr. Bystryn is a member of the American Association of Immunologists, the Society for Investigative Dermatology, as well as many other dermatological professional societies. Dr. Bystryn recently attended the Foundations' Annual Doctor/Patient Meeting held this year in New York at the NYU Medical Center. He spoke about PV treatments such as IVIg.
ing care of their teeth and gums. This can cause tooth decay, recession of the gums, and bone loss. These problems can sometimes become quite serious. Occasionally, for example, it is necessary to attach dentures, which can be difficult if the gums are severely damaged. In these severe cases, tooth implants may be necessary.

Dr. Strois believes that the dental community should be better informed about pemphigus and pemphigoid. Dentists should ask the following questions when a patient complains of oral lesions: How long have there been lesions? Is it a recurring problem? Are there multiple lesions in the mouth? The answers to these questions may indicate that a biopsy is necessary to definitively diagnose pemphigus or pemphigoid. Unfortunately, because many dentists are not familiar with these diseases a biopsy is often not taken or is often not taken properly. For the best possible outcome physicians and dentists need to work together.

Pemphigoid was then discussed by Dr. Dina Began, Department of Dermatology, NYU Medical Center. Dr. Began discussed the difference between bullous pemphigoid (BP), and cicatricial pemphigoid (CP), also called mucous membrane pemphigoid. Both diseases tend to occur equally in men and women over 50.

BP is much less serious than CP. BP lesions look like hives or bumps, and usually occur in the extremities and under the arms. The bullae can be quite large. The lesions itch more than CP lesions. In 10% of patients, the disease can affect the oral cavity, and in women it can affect the vagina. Diagnosis is made by clinical history, but a biopsy is recommended for confirmation. Blisters occur between the epidermis and the dermis—the upper and lower layers of the skin. Topical antihistamines can help reduce itching. Also effective are cool compresses and cool baths. These topical treatments may be effective. However, systemic therapies, including prednisone in combination with an antibiotic or an immunosuppressive drug, can be more effective, and are used when necessary.

CP is a much rarer and a more serious disease. The hallmark of this disease is scarring. It presents in the eyes, mouth, and the skin. Because of the scarring, it is important to treat the disease aggressively so that blindness or stricture of the airways does not occur. The antibiotic Dapsone® seems to work well, as do immunosuppressives such as azothiaprine. CP can vary in severity.

Dr. Victoria Werth, Department of Dermatology, University of Pennsylvania, Philadelphia, focused on bone loss, a side-effect of steroids. This is an important issue, since osteoporosis is a common side-effect of steroid therapy. Thirty to fifty percent of patients taking steroids get fractures. This can occur not just on high doses of steroids, but on doses as low as 12 mg a day. Even 5 mg a day can cause a 2% loss of bone. Spinal fractures are especially common. The rate of bone loss is greatest in the first six months of steroid use. The bone loss then continues, but at a slower rate.

Groups at risk for developing osteoporosis are post-menopausal women, patients whose diets lack Vitamin D and Calcium, and smokers. Patients taking thyroid medication, cyclosporin, or a “blood thinner” such as coumadin are also at risk for developing osteoporosis.

Dr. Werth recommended that anyone who has been on steroids a long time should have an annual scan of the lumbar spine, and, if over 60, the neck of the femur. She also suggested that weight bearing exercises, avoiding smoking and alcohol, and taking at least 1500 mg of Calcium a day can have a positive effect on stemming bone loss. There are also drugs that can be taken to build up bone, such as Fosamax® and Actonel®. Other drugs with a low incidence of side effects are being developed for osteoporosis.

Barbara Sipe, RN, Department of Dermatology, University of Pennsylvania, Philadelphia, discussed the nursing aspects of pemphigus. She related that nursing care for pemphigus patients includes two main aspects: wound care and psychological support. Pemphigus lesions resemble second-degree burns. The best care is Vaseline® and gauze. Contrary to popular belief, for better healing wounds should be covered, not exposed to the air.

Psychological support is just as important as the care of wounds. A new patient has many concerns. Not only does a patient have to deal with the disease, but he also has to deal with the problems of the medical system. Nurses can help calm a patient who is angry and frustrated. A nurse can help patients understand what they read about the disease, discuss the psychological aspects of the disease, and talk about the drugs and their side effects. Pemphigus can affect the whole family, and the nurse can interface with the family and answer any questions the family members may have.

Ms. Sipe recommended that it was important not to wait until the next appointment if new lesions start to show up. Call the doctor’s office immediately, and ask to speak to the nurse. Also ask to speak to the nurse if you have pemphigus and cannot get an appointment in a timely manner. Many of the expert physicians understand the importance of prompt treatment, and they will try to fit you in as soon as possible.

Good nutrition and regular exercise are very important. Try to avoid stress. Consider speaking with a professional counselor or therapist. This can be very helpful to both patients and their families. Ms. Sipe also stressed that pemphigus patients should take time each day for him or herself—to do what you want to do and get plenty of rest. Finally, she emphasized that the best combination for the best care is the patient, physician, nurse, family, and friends working together.

The next two sessions focused on the research aspects of pemphigus. Dr. Jim Rasmussen, Peptimmune, Inc., a biotechnology company in Boston, was the first to speak on this subject. Dr. Rasmussen discussed the work Peptimmune is
doing to develop a “vaccine” to treat pemphigus vulgaris. The Peptimmune drug is designed to shut down production of autoantibodies against desmoglein 3, a protein in the “glue” of the skin and mucous membranes. It is believed that the breakdown of desmoglein 3 by auto-antibodies causes PV. Inhibition of auto-antibody production, therefore, would stop the breakdown of the skin and the formation of lesions characteristic of pemphigus vulgaris.

Before it is approved by the US Food and Drug Administration and becomes commercially available, the vaccine must be carefully tested to assure it is both safe and effective. First, Peptimmune must do a study to satisfy the FDA’s requirement that the drug is safe for human subject testing. Peptimmune hopes to complete this study by the end of 2002. Then, the drug must be clinically tested in a series of trials called Phase I, II, and III. A Phase I clinical trial determines the safety profile of the drug. A Phase II trial is a small clinical trial to determine the proper dose and administration of the drug. Finally, a Phase III trial studies efficacy and safety in a larger population of patients. The FDA will approve a drug for market only when their strict criteria for safety and efficacy have been met.

The studies will be carried out by physicians at various clinical sites. Peptimmune hopes there will be six to eight clinical sites. There will be specific criteria for patient participation. Eligible patients will be identified by the clinical researcher. Clinical trials will only include adults – no children or pregnant women.

Peptimmune is guardedly optimistic that a Phase I clinical trial will take place in the first half of 2003. The timetable for the Phase II and Phase III studies depends upon the outcome of the earlier studies. Dr. Rasmussen emphasized that there is still a good deal of work to be done before the drug is given final approval.

Next to speak were researchers from the laboratory of Dr. Animesh Sinha, Department of Dermatology, Weill Medical College of Cornell University, New York. Dr. Sinha’s researchers, Yasmin Pirani and William Miele, spoke to the group about their current pemphigus research. As they introduced their presentation, they made it clear that it is difficult to distinguish the initiating elements and events in pemphigus from the perpetuating ones. Their work centers on finding the various epitopes (small sections of proteins) which elicit T-cell responses which, in turn, trigger the immune system to produce autoantibodies. They have found several such epitopes. One therapeutic potential of their research is a targeted disruption of the auto-immune sequence. With the genetically unique nature of one’s immune system, individualized immunoprevention is also a possibility. And finally, specific mechanisms, such as synthesized peptide ligands to bind to antibodies in place of desmoglein, T-cell antagonists, tolerization with peptide antigens, and even gene therapy aimed at autoimmunity are also potential therapies which could result from Dr. Sinha’s current research.

The afternoon began with a question and answer session. There was lively discussion between the morning speakers and the audience, as well as between the various presenters. The subjects ranged from whether a person with pemphigus should go out in the sun, what should be done if a flare occurs, if hair loss from the lesion is permanent, to whether physicians were willing to consult with one another on difficult cases. As there were many questions asked and we cannot cover all the Qs and As in this column, we will address these specifically in our Q and A column over the next several issues.

Our final session was a panel of patients from different backgrounds and perspectives who spoke about living with pemphigus. While each speaker related his or her unique, personal experience, they all agreed that getting a proper diagnosis had been one of their biggest problems.

Matt said that he had learned that he needed to be his own advocate. He also believes that all patients with pemphigus should keep a detailed record of blood tests, lab test, and doctor visits.

Robyn, a young adult living with pemphigus, talked about how difficult it is for a young person to be correctly diagnosed. Doctors were reluctant to believe that pemphigus could be the diagnosis in a 26-year-old. Getting her family involved helped her get the diagnosis she needed. At the meeting, Robyn met other young adults who are coping with pemphigus. She feels strongly that having support from friends and family is very important. It made a big difference in her life.
Sloan, despite being diagnosed immediately, had one of the worst cases of pemphigus known. Within 5 weeks she had lost most of her skin. She was admitted to the burn unit of her hospital and spent a considerable amount of time there. Sloan believes that positive thinking and a good sense of humor are very important in the healing process. She believes that meditation and positive visualization are also extremely important. She strongly believes in the importance of the mind, body, spirit connection. She does not like to use the word remission, but truly believes she is healed. She is now off all drugs and has no evidence of the disease.

It took Terry, a psychotherapist, seven months to get a proper diagnosis. Terry understands that we are human beings, and that having pemphigus is just part of who we are. She had terrible problems with gastrointestinal disease, so prednisone was not an option for her. Terry started on IV Ig therapy, which works quite well for her. She believes strongly that if someone has depression due to the disease or the drugs he or she should speak to a counselor or therapist. She supports the Foundation's discussion group, which is made up of many people sharing information about pemphigus and pemphigoid. She feels it is very helpful in providing both information as well as emotional support. Terry was also pleased to meet two people at the meeting who live near her who she did not know before.

Our fifth panel member was Ruth. Ruth is a nurse and could not believe that she could be so sick. It got so bad that she could not eat or even drink water. Ruth spoke about staying positive and believing she was going to get better. Maintaining a positive attitude helped her a great deal. She echoed Barbara Sipe's statement that nurses can provide important compassionate care. They will also answer many questions that busy doctors do not have the time to address.

Several members of the audience spoke about their experiences of living with their disease. Robyn closed the session by mentioning how important it is for us to help each other learn about and deal with our disease.

The day ended with comments from Janet Segall, Executive Director; and Jean Barish, President, Board of Directors President. There was also a drawing for two free nights at the New York Helmsley Hotel, and the screening of our new promotional video, which was put together to help people understand the mission of the Foundation.
A Systematic Review of Treatments for Bullous Pemphigoid

Nonhlanhla Khumalo, Dedee Murrell, Fenella Wojnarowska & Gudula Kirschig

Archives of Dermatology March 2002 Vol 138 pages 385-389
www.archdermatol.com

This review is different from the usual type of review you might read about bullous diseases in that by being “systematic” it was submitted ahead of time to an independent panel of editors at the Cochrane Collaboration for Evidence-Based Medicine stating that the aim was to summarize data from randomized controlled trials (RCTs) only for the treatment of BP. In addition, how those trials are to be searched for, analyzed and compared is scrutinized. Out of all the databases only 6 RCTs were published, including 293 patients. One trial compared prednisolone at different doses: 0.75mg/kg/day vs 1.25mg/kg/day, and another compared methylprednisolone with prednisolone, and neither study found a significant difference between the two groups, but the patients on the higher prednisolone doses had more severe side effects.

Two trials were of combination treatments: (i) prednisone vs prednisolone and azathioprine (Imuran) and (ii) prednisolone vs prednisolone and plaquenil exchange; these combinations roughly halved the steroid dose needed to control BP.

One trial had 3 comparisons: prednisolone vs prednisolone and azathioprine vs prednisolone and plaquenil exchange; that trial did not show any benefit of these combinations over prednisolone alone.

The last trial compared prednisone to tacrolimus and niacinamide, and found no statistical difference in response between the two groups, but the side effects were higher in the prednisolone group.

The drawbacks of each of these studies are highlighted. This is a useful paper to read if you want to learn more about how studies for the treatment of bullous diseases should be performed.

Four of these studies were conducted in France, and the French group since published a further RCT in the New England Journal of Medicine comparing topical colchicin vs oral prednisolone for BP.

Comment:

I personally believe that dermatologists should try to collaborate more and try to do more RCTs for the rare conditions such as BP and Pemphigus to try to determine which are the most efficacious treatments, best dosing regimens, etc. To my knowledge RCTs are currently enrolling at various centres in the world (coordinated by Dr Vicky Wirth in Philadelphia and at St George Hospital in Sydney, for the dapsone as a steroid-sparing agent in patients with pemphigus vulgaris in Germany for various PV treatments, and in France, on-going trials in BP.

Contributed by Dr. Dedee Murrell, Sydney, Australia. ☡

ELISA – Peace of Mind by the Numbers

by Kirsten R Bellur

It is almost four years ago that, after many failed attempts, I was finally accurately diagnosed with pemphigus. In the face of that solemn pronouncement, I was told there was good news: it was only localised, a more benign form, that was easily treatable with prednisone. And under that treatment it would most likely go away. But this sanguine vision and mitigating explanation of the seriousness of the illness did not obliterate the fact that I was unable to regain the integrity of my skin.

As others living with this condition have experienced, after several months of prednisone, alone, I did not get a favorable result. Therefore, Imuran was added to the drug regimen. After four months, the side effects were too intense, and my steroid-sparing drug therapy was changed to CellCept. For almost two years, I did a “yo-yo” diet of steroids. I was down to 9mg of prednisone every other day, only to experience a flare, necessitating a difficulty steep, fast-track steroid schedule to combat it, one which my body was ultimately unable to follow. After almost 6 months, I reduced to 20mg of prednisone a day, and experienced another flare. And I was advised, once again, to go back up to a high dose of prednisone.

Going up and down repeatedly on prednisone, I was losing faith that I was making any progress whatsoever, and suffering serious side effects. When dealing with PF, one can never ignore an itch or a blister, as it may well be the harbinger of a flare-up of the disease. This flare-up would have been building precipitously beforehand with no visible signs and has now, with perceptive manifestations, reached a level that is more advanced, requiring higher doses of medications to get it under control. Was there any way to accurately predict a flare-up before the itching started, when the antibody levels were lower, and less of the harsh medications would be required to quell it?

My desire to answer that question became even more urgent as I analyzed my drug therapy over time and came to an alarming possibility. For every subsequent flare of the illness, more prednisone was required, and for a longer period of time, to suppress it. The “yo-yo” diet seemed, perhaps, somehow to be making the illness less responsive to the medications. The implications of this, given the deleterious side effects of prednisone, could be dire.

Desperate to make progress toward remission, I sought answers widely, leading me to Dr. Grant J. Anhalt at the Johns Hopkins Medical Center. He met with me and assessed my condition. His first observation was that my dosage of CellCept (2000mg/day changed to 1500mg/day increased again to 2000mg/day), though appropriate for certain organ transplants, would most likely be more effective for PF at the higher constant dose of 3000mg/day. But the most valuable insight was this: the
Enzyme-Linked ImmunoSorbent Assay (ELISA) test may be able to predict flare-ups before they manifest themselves as perceptible symptoms, allowing them to be suppressed with a smaller amount of medication. The ELISA test is better at assessing this than the commonly used Indirect Immunofluorescent test (IIF).

The ELISA test provides a sensitive, specific, and quantitative tool to obtain precise information about autoantibody specificity. Monitoring the disease activity can be extremely useful in planning a tapering schedule for prednisone and predicting flare-ups and relapses by detecting increases in antibodies before clinical evidence is noticed. Early intervention is the best defense. One could, therefore, then imagine taking the ELISA test monthly, and when a rise of antibodies seemed to be happening, well before the patient could feel it, the medication could be raised slightly to stop a flare. The implications to the patient, who could be spared dangerously high doses of harsh medications, are staggeringly positive.

Such a discovery faced some adversity: getting my health insurance provider to cover the cost. Very typically, a myopic view about the ultimate cost savings of preventative, proactive care most likely led them to this decision. After they first denied coverage, I filed a grievance with their Medical Review Board, and backed up my claim with relevant articles and research. With no background in medicine, this was an intimidating task, but I knew that I was fighting for the very quality of my life. Without going into all the details, my request was granted— they would reimburse the cost of the test.

The blood collection for the ELISA test is very simple, and can be done from anywhere (I live on the other side of the country from Johns Hopkins). I am provided with pre-paid mailers that the local lab uses to express mail the samples to the Johns Hopkins Lab. My primary care physician has filed a standing order for monthly completion of this test, along with Complete Blood Count and Hepatic Function Panel (CBC & LFT’s). All the tests results are also communicated to my dermatologist, an outside provider. Initially the ELISA test should be done monthly and then, with progress, can be done every three months, as the antibody levels neither increase or decrease at a rapid rate.

It has given me great comfort and peace of mind to get the ELISA values as an added assurance, that the occasional itch or blister I experience is not my next flare or relapse, but that I may finally be on the track to a durable remission. It is also important for me when faced with making informed decisions with regard to other medical matters that affect my life – like elective surgery, as I have experienced first hand, medicine is not an integrated art, but the art is to find the right medicine.

I hope sharing my personal experience may help others find the right treatment.
Pemphigus: An Ayurvedic Approach

Jay Glazer, MD is a board-certified internist, researcher and medical director at the Lancaster Ayurveda Medical Centers based in Sterling, MA. He can be reached at 978-423-5044. Answers to many questions about Ayurveda can be found on the Lancaster website, www.AyurvedaMed.com, where you can subscribe to their free online newsletter, The Spirit of Health.

Sufferers of pemphigus are in a good position to aid well meaning administrators in politics, social policy, security, intelligence and defense who are currently grappling with how to re-engineer a free society immune to disruption from within or without, because this disorder recapitulates issues in domestic security. Understanding the immunology of autoimmune disorders sheds light on critical issues of individual and societal health, so we will examine immunology from both a western and eastern perspective.

A Sanskrit expression from Chaanka Samhita, the oldest textbook of medicine, states, yatha pindde tatha bruhtmnde, i.e., "as is the individual physiology, so is the universe." This means that the body is an expression of the underlying field of intelligence, the same intelligence that also governs the functioning of larger structures such as galaxies, ecosystems and societies. In the wake of recent horrific events, we have all wondered if there is any intelligence at all at work in a human society. Quantum mechanics and chaos theory both insist, "Yes! But like biology, it is an intelligence that operates with probabilities and uncertainty." This also means that social systems have their own physiology.

The ancient Ayurvedic texts call this intelligence Veda, and describe it as a blueprint for the physiology, indeed for the cosmos. Veda functions as a constitution of the universe, describing the laws of nature at work as unmanifest, unexpressed intelligence that expresses itself into human, a virus or a star. The verses of Veda and the Vedic literature also have a discrete structure, an architecture defined by the relationships between the syllables, words, chapters and rhythms.

If Veda indeed provides the blueprint for nature including for humankind, one would expect that human physiology and anatomy reflects the architecture and functioning of Veda. Tony Nader, MD, PhD, a Harvard-trained neuroscientist investigated whether the structure of Veda could be found in the human neuroanatomy. Dr. Nader analyzed all 40 areas of Veda and the Vedic literature and discovered that each Vedic text has an almost identical corresponding structure in the human anatomy. For example, RG Veda, the primordial Vedic text which gives rise to all others, is composed of 192 groups of verses. Similarly, the human autonomic nervous system governing our vital functions consists of 192 nerves.

This recent insight from neuroscience provides one of the strongest confirmations of the existence of an underlying blueprint for creation and that every human individual is cosmic. This correspondence also validates the biblical understanding that man is made in the image of the divine.

Agnivesha, a medical student who lived thousands of years ago, poses in the ancient Ayurvedic medical text a question about immortality that is still pertinent today. "Why is it that some people eat all the right things and they still get disease and infections, while some people never eat well and they seem to never fall sick?" His professor, Atreya, gives an answer that prophesies our modern understanding. "Predisposition to disease also depends on how and when the food is eaten, the environment of the individual, as well as on genetics."

Immune disorders, like problems with security systems or militias, can be categorized as either 1) weak immunity or 2) strong immunity, but lacking organization and leadership. AIDS is an example of the former because the immune cells are both scarce and weak. Pemphigus and other autoimmune disorders and allergies are examples of the latter. In allergic conditions, a strong immune system aims its formidable weapons at a non-threatening foreign irritant, the proverbial cannon against the mosquito.

Autoimmune disorders are the most interesting to a student of social policy and domestic security because they represent an imbalance between adequate internal vigilance and tolerance of individuality. Autoimmune diseases are caused by activation of immune cells for no apparent reason such as an infection. The
immune response is directed against one's own tissues, perhaps tissues that, to a T cell, look a lot like an invader. This includes not only pemphigus, but common disorders such as hypothyroidism, rheumatoid arthritis, psoriasis, juvenile diabetes and probably multiple sclerosis, as well as more uncommon problems such as lupus, spondylitis and inflammatory bowel disease.

Immune cells are not designed simply to discriminate self from foreign, but to attack in an environment of inflammation triggered by chemical signals. Autoimmune disease usually implies both a genetic predisposition and the presence of triggers such as viruses or bacteria, drugs, a woman's natural estrogen or even stress. It seems that Atreyu was right: genes and one's environment are just as important as a good diet.

Pemphigus and other immune disorders of the skin may be more common than immune disorders involving other organs simply because the skin, our largest organ, is responsible with the toughest immune task in the body: keeping the interior sterile in the face of an unsterile hostile environment. The intelligence to accomplish this difficult task, according to Ayurveda, comes from the source of intelligence in Veda, whose first biological expression is our DNA.

The standard medical approach is to subdue the immune system using harmful steroids and other risky immune suppressants otherwise used for preventing transplant rejection. Continuing our analogy, this is comparable to so weakening the FBI and other domestic security agencies, simply because they lacked perfect discrimination between the innocent citizenry and subservient, that it endangers the whole society.

It has long been known that stress aggravates allergic disorders like asthma, eczema and hives. What experienced ER doc hasn't seen kids with severe wheezing at home, who are fine as soon as they enter the hospital, knowing that they wouldn't suffocate? Now several studies have shown that stress can also be a trigger for autoimmune disorders, including Grave's disease, lupus, colitis, and rheumatoid arthritis. Our forebears fleeing a saber-tooth tiger had a good chance of being wounded, and needed an immune system that would be mobilized and stimulated from the chase alone. Today the tiger and its like are extinct, but we go about our business with our nervous systems in high gear as if these dangers were present, creating neuropeptides and stress hormones in the brain that circulate through our bodies to turn our immune systems on inappropriately. Serenity, on the other hand, allows proliferating cells to be quiescent.

So intimately are the nervous and immune systems connected that a new science called psychoneuroimmunology has arisen that may make this connection not only legitimate but also practical. Brains and immune cells both have memories and intellects, and even share some common cells. Most importantly, a nervous system free of anxiety and depression creates a neurochemistry that signals the immune system to deactivate. Countries at peace, like Switzerland and Costa Rica, marshal small, inconspicuous armies.

The western approach to pemphigus and other autoimmune disorders is to take corticosteroids and other powerful immune suppressants. The Ayurvedic approach to autoimmunity is to put the immune system to rest rather than to suppress it. Transcendental Meditation has been shown to improve the inflammatory response of gingivitis and to lower cortisol and increase DHEA, exactly the opposite of the stress response. Several Ayurvedic herbs, including guggulu, have powerful anti-inflammatory effects and have been shown effective in rheumatoid arthritis, the autoimmune disorder that wreaks the most widespread suffering.

When I was in medical school, we thought that the body naturally eliminates clones of cells that attack one's self, leaving intact only the T and B cells which react against foreign antigens such as bacteria. Now we understand that a low level of autoreactivity is natural and even critical to normal immune function. Apparently, tissues that provoke an immune response help naive immune cells to differentiate and survive. In addition, since our bodies create cancer cells every day, a hint of autoreactivity may be one of the ways the immune system is recruited to eliminate these abnormal cells, which don't look quite like "self."

It seems that the healthiest condition for the body is akin to a benign yet restful society that is perpetually challenging the domestic security agencies to keep them on their toes. In these challenging times, may we have the humility to take a few lessons from Nature in establishing our new world order. Perhaps we can take a few lessons from the ancient sages of Ayurveda in overcoming pemphigus.

San Francisco Bay Area  
Janet Segal, Executive Director  
510-577-4970, Email: pemphigus@pemphigus.org

Los Angeles  
Barbara Roller  
818-991-6569, Email: barby43@aol.com

Dallas Ft. Worth  
Angela Vickers  
817-557-9642

Houston  
Richard M. Schwartz  
713-721-1178, Email: richardm@hal-pc.org

Philadelphia  
Barbara Sipe  
215-662-6446

Baltimore  
Erica Byrne  
410-964-1099, Email: gusdarwin@home.com

New York  
Joan DeLucie, NPF VP  
516-586-6910, Email: jdelucie@aol.com  
Matt Koenig  
516-825-4594, Email: mattske@aol.com

Midwest Support Network  
Mike Main  
630-579-0134 (Hm), 630-968-6880 x229 (Wk)  
Email: mmmain@chapterhouse.com

England  
The PV Network  
Fiat C 26 St. Germans Rd., SE 23 1RJ,  
(Enclose stamped, self-addressed envelope)

Toronto  
Dan Goodwill  
416-488-0493, Email: damgood@ican.net

Rome  
Anna Lisa Riccardi  
Email: ariccardi@libero.it

Online  
Eileen Lucey  
Email: elucey@ mindspring.com

Website  
www.pemphigus.org  
webmaster@pemphigus.org
Pregnancy & Pemphigus Can Go Together
by Fariba Vakilpy

I t was March 19, 1991, that they diagnosed me with pemphigus. It was the fourth appointment in the dental office. I came back home and I noticed a lesion in my mouth. The doctor didn't know what was wrong. They sent me to the oral surgeon. He gave me some medicine to wash my mouth with. It got worse so they sent me to my Dermatologist and they did the biopsy. They said it was pemphigus vulgaris (after two months).

They started me on 40 mg of prednisone. At that time, I was going to college and I was married for three years. I was too young to have this serious disease. After 9 months, I saw Dr. Lozada-Nur at UCSF for a second opinion. She started me on Imuran. I got better, but because of my curious nature, I am always researching articles and magazines about this disease and people who had it years ago and what happened.

The first two years I was in denial because I was too young for this trauma. I hadn't finished my college and I didn't have a baby yet. Until 1994, I was off and on prednisone and Imuran. In 1994, I finished college and I decided to get pregnant because it was time to have a baby, and I hoped to get better by changing a lot of hormones in my body. But, unfortunately, I got much worse and with a lot of complications including: diabetes, premature labor, recurrent infections. But, someone, somewhere, wanted me to have this beautiful and healthy baby boy without any blister on his body.

I had the worst condition that anyone could imagine after two months of my c-section. Again, I was on high dose of prednisone and Imuran for two years. During these years, I always was searching for any alternative medicine or herbs. I tried Chinese herbs for a while, but because of the medicines that I was taking, I didn't have a lot of good results. I saw a nutritionist and I learned a lot of good tips about nutrition. I changed my eating habits.

I bought Eat Right For Your Type and it helped me a lot. Gradually, I got better, but not in remission. In 1997, I saw news in the Foundation’s Quarterly about a new drug called CellCept that has fewer side effects than Imuran. I asked my doctor to change my medication. I was taking it for two and a half years. By the way, I was under the care of a good specialist at Stanford Medical Center by the name of Dr. Peter Marinkovitch by that time. I forget to mention that from 1994 I found an angel called Janet (at the Pemphigus Foundation). She helped me a lot with all the information that I needed.

Because of my age, and a lot of responsibility that I felt toward my baby and my very supportive husband, I always wanted to get free of this horrible disease, so I asked my doctor about any other procedures that were available. He told me about IVlg. It was so new for me, and at first, I was a little scared. After a little bit of research, we were convinced to do it. In August, 1999 everything was ready. They did the IVlg for six months and I got much better. So because of the good results after three months, they did another six months. By that time, my precious mom was here to help me emotionally and physically.

By August 2000, I was free of pemphigus. I was still taking 20mg of prednisone (every other day) and after three months later, I stopped the prednisone with the permission of my doctor. Now I am writing this letter in 2002. I am free of pemphigus with a zero titrer count twice.

I wanted to tell you that after they finished the IVlg, I was so happy and at peace with my life after nine years. I didn't have to go to the cabinet every night to take these medicines. However, after one month of finishing IVlg, I received a call from my sister that my mom, age 54 passed away (because of the disease that she had for years).

That night I said to myself, I really believe now that life is like school — you graduate from one exam and then there is the next one! Believe me, some human beings have more difficult lessons than others. Never say, “Why me?”

All these years I never lost hope. I followed my heart. I tried my best and GOD helped me to find the way. Good luck to all of you guys. I am always willing to help anyone who needs any information about the things that I have done so far. (My phone number is in the Heart2Heart section of the Quarterly) The names of the books that helped me this battle:

- Eat Right For Your Type
- Creating Health by Deepak Chopra
- Spontaneous Healing by Dr. Andrew Weil
- Meditation classes and practicing a lot at home
- Yoga exercise

QUESTIONS & ANSWERS

If you have questions you would like answered, write to us at the Foundation and we will try to find the answers and include your question in one of the following issues. If applicable, we will have a doctor answer these questions. The answers in this issue were all given by two of our leading physicians.

Q. Can an assessment of remission be made from biopsies of uninvolved skin?
A. There is some validity to that approach for the following reasons: Detecting low levels of persistent antibody in the blood is difficult using conventional immunofluorescence. (However, it is better when one uses the ELISA, which is much more sensitive.) So, antibodies may persist, a sign of still active disease, and only be detectable in the skin, using immunofluorescence. Most people in remission still have persistent antibody, and require continuous treatment, although often with lower levels of prednisone or other drugs. A small number will have a true remission, without detectable antibody in the blood or the skin, and will be more likely to continue in remission, even after drugs are completely withdrawn. This has been studied previously, by a group in Israel, and I have cited the reference: The usefulness of immunofluorescent tests in pemphigus patients in clinical remission. British Journal of Dermatology 1989; 120: 391-395. Dr. Anhalt
One Man’s Road to Remission and Beyond

by Skip Van Lenten

I was once asked by a member of the online discussion group to explain how I was lucky enough to be in remission for four years. The answer is, I’m really not sure.

At its worst, within the first six months of contracting the disease, I had reached a point of emaciation, and could not get out of bed. I had lost 41 pounds, was unable to eat, and had gone too long without proper treatment. I was completely exhausted and possibly near death. I actually felt as if I was leaving my body, and I didn’t care.

My wife and sister collaborated to convince my doctor that I should be admitted to a hospital, Yale-New Haven, and from there I started the long road back and the experience of coping with prednisone and all the other drugs. I have been totally off all medications and completely free of any blisters since the summer of ’98. I had tapered off prednisone by January of that year, and continued on Imuran at 100mg per day, until things flared up again about a month or so later. I had to go back on a heavy program of prednisone to control it (80 mg for 4 days, 60 mg for 4 days, then 40 mg for 4 days, etc., to 0 mg again), and it stopped the blistering and the flare almost immediately. That’s not to say that I didn’t continue to experience any pain, or have difficulty with some foods—the activity of blistering was over, but the many remaining hot spots and lesions had to be healed.

I would say it took about 6-8 months, or possibly longer, before all of the spots were cleared. The side effects of prednisone were also slow to resolve. They continued to haunt me for at least a year, but I do remember a very distinct moment when I suddenly realized that my body had successfully rid itself of all of the drugs and their side effects. It was like I was suddenly normal again, and since that time, my mouth and body have been completely healed up and free of any blisters.

As far as losing time at work, I am a housepainter by trade, which is tough enough to do without having Pemphigus, but I managed to work at least 15-20 hours a week within a month or so of being released from the hospital. A lot of other factors came into play, but being self-employed, and pretty much working alone, it wasn’t as hard for me to pace myself as it might be for someone who has to be at a particular job at a certain time each day, and remain there for 8 hours or so. I could go home if I didn’t feel well, or sit down if I got too fatigued (which was the main problem for me, and I guess a side effect of the drugs). Since I have had more than my usual amount of time to participate in the online group lately, I have been thinking a lot about the things that led up to going into remission, and how it was that I came down with Pemphigus in the first place.

Maybe having studied psychology, and earned my master’s degree in clinical psyche, or just because I try to approach a problem by taking all possible factors into consideration, I look at my own experience with it in very subjective terms. If I could explain what I mean by that, it would go something like this: before I came down with my first blister in November, 1994, I had gone through a long period of stress in which I was emotionally confused and felt “trapped” in a relationship I wasn’t sure I wanted to be in. I don’t want to bore you with the details, but I think in a situation where there is prolonged stress, the immune system, whose function is to fight off foreign intruders in the body (i.e. bacteria, viruses, etc.), could become overloaded (heaping the emotional turmoil on top of all of the other thousands of “invasions” that it has to deal with), and become confused enough itself to start over-producing antibodies which then go on to attack healthy tissues and cells. I know that sounds almost like a cartoon description, but it was in that state of mind and emotional stress that my system broke down and I began to develop my first blisters. Over the next four years, I went through a number of treatment formats, always including prednisone and some form of immuno-suppressant, and experienced the same kind of yo-yo effect of tapering down and experiencing flare-ups that seems to be common to all cases. I can look back and see myself as two different people. What distinguishes the kind of person I was before I came down with the disease, from the person I was prior to going into remission, is very simple: I learned how to relax. It took me several years before I realized how important it was to listen to my body, and to use my symptoms as a guide (in choosing which foods to eat, for example, or avoiding stressful situations). I went into therapy, I talked about my feelings, I bought relaxation tapes, studied hypnosis and self-hypnosis, took a lot of walks in the woods, sat by the river, and spent a lot of time physically letting my body and mind unwind. I’m sure this wasn’t the only factor involved in remission, and I would never suggest that simply relaxing is a cure for Pemphigus, but I think it did play a role in sending the message to my immune system that it was alright to relax, to settle down, and to stop shooting at everything in sight.

I don’t know how much control we have over the functioning of internal organs, but there is a whole field of self-help books and psychological programs out there that deal with relaxation-imaging techniques for everything from helping to reduce tumors to overcoming migraine headaches. Why not Pemphigus? To sort of round things out from the “alternative” perspective, I was also taking a number of vitamins and minerals to replace those that are depleted by prednisone. Common sense would dictate that if you take a drug that destroys calcium, for example, you should find a way to replace it. That was a part of my treatment program, but something that I had to research and formulate for myself. A good place to start is a food allergy test. Medically speaking, I guess I could say that I hit upon the right combination of prednisone and Imuran, and that I consider these two drugs to be crucial to controlling the disease right from the start. I was given other immunosuppressants in conjunction with prednisone, but none worked better for me than Imuran. I was also fortunate enough to come under the care of a cancer pain specialist at Yale-New Haven who suggested that the doctors prescribe MS Contin, which is a twice-a-day, timed-release morphine tablet that is truly a God-send to anyone in serious pain. It became a staple of my treatment for as long as I needed it, and when the pain subsided on its own from time to time, it was no problem to get off of it. I consider pain to be one of the worst symptoms of Pemphigus, and a co-conspirator in prolonging the illness. It creates a level of stress that is nearly unbearable, and by doing so, it hinders the body’s ability to focus on anything else and makes healing even more difficult. I hope that more and more doctors will begin to treat pain as aggressively as possible, and worry less about
the possibility of addiction. As my own doctor put it at Yale-New Haven, "If it happens, we'll treat that too!" That kind of confidence is inspiring, and implied a faith in my ability to control my own destiny that was invaluable to the rest of my treatment program.

My thinking on Pemphigus and how I got to where I am today keeps evolving, and I am trying to recall what I did and what it was like to have the disease, so I am trying to keep up with my own thoughts and provide as much information as I can to members of the [online discussion] group. I am willing to do whatever I can to help. I'm no expert in the disease, or how to treat it, but I have the personal experience of having been there and recovered, and I would be willing to share that with anyone who might be interested.

**FOUNDATION NEWS**

**IPF Releases New Video**

It began with a conversation over a cup of coffee in the Soho neighborhood of New York with pemphigus patient Eva Gold, her husband Eric, and IPF Board President Jean Barish. Two years later, the IPF was pleased to release its new video at the recent New York doctor/patient meeting. The positive response to this video has been very heartwarming.

Thanks to the talent and hard work of Eric and others, we now have an informative and moving video that tells the story of the Foundation, explains medical aspects of pemphigus, and introduces viewers to members of our community. We hope this video will help our outreach efforts, and we believe that anyone who sees this video will come away with a better understanding of the disease and the importance of the Foundation.

Our deepest appreciation to Eric Gold for producing this wonderful video. Our thanks to Jean Barish who worked with him on the production, and to everyone who gave their time to be interviewed. Thanks, also, to Dimitri Karas, Sound Greetings, New York, New York, who so generously reproduced the video for free to help us spread the word.

If you would like a copy of the video, please contact the IPF office. The video is free, but there is a small charge of $5.00 to cover shipping and handling.
The International Pemphigus Foundation recently published its new web site. The primary focus of the web site is to provide accurate information about pemphigus and pemphigoid for patients, doctors, and others seeking knowledge of these autoimmune disorders. Since information about these diseases has traditionally been difficult to find through conventional channels such as books, magazines and the family doctor, the Foundation's web site has quickly become one of the most comprehensive, accurate and up-to-date resources for doctors and patients alike. It has helped thousands of people in either ruling out pemphigus/pemphigoid, or in obtaining accurate diagnoses for themselves or family members and friends.

Another important part of the web site is the patient support channels provided there. Instructions for participating in the email discussion group, a cornerstone benefit of the Foundation, is provided in the Patient Support area of the web site. Participants in the email discussion group consider it an indispensable part of their road to recovery. First-hand patient experience, advice and encouragement are among the many helpful benefits of the discussion group. The first responses to questions are often answered in just minutes, and generally, multiple perspectives are provided within the first 24-48 hours.

In addition to the discussion group, the Patient Support area of the web site also provides traditional means of contact with a listing of local area support groups, as well as telephone, address, and email listings for dozens of volunteer support people in more than 20 states in the USA, and in several other countries of the world.

Patients in need of referrals to qualified medical practitioners will also find help in the Patient Support area.

The Publications section of the web site contains previously published medical, news and feature articles from past issues of the Quarterly. This information is kept current, and is reviewed by the Medical Advisory Board for accuracy. Other Foundation publications are also available in this section.

Information about the Foundation itself is also available on the web site, including how to donate to the Foundation, its mission statement, history, board of directors, and Medical Advisory Board.

Suggestions for improvement are welcome and should be directed to the email address: webmaster@pemphigus.org. The Foundation's web site address is www.pemphigus.org.
If you need to talk to someone about pemphigus, contact one of our volunteers.

Alabama
Arizona .......... Sloan Stevens .......... 920-814-1348
Tucson ..........
California
Chino .......... Sandra Rose .......... 909-391-1946
Chula Vista .......... Al Smith .......... 619-426-2769 .......... alsmith45@aol.com
Long Beach .......... Seina Tramel .......... 562-430-9472 .......... stramel@sta.com
Pleasanton .......... Jarita Vadehy .......... 925-426-7445
Santa Monica .......... Venus Restegi .......... 310-567-2190 .......... bijuspoon@yahoo.com
Tehachapi .......... Lillie Ann Swanson .......... 661-821-2229 .......... lvorseone@highspeed.net
Colorado
Denver .......... Esther Lustig .......... 303-773-6205
Florida
Tallahassee .......... Lee Ketrick .......... 850-893-5538 .......... d281994@nettally.com
Loughman .......... Guy Harsworthy .......... 407-532-1311
Georgia
Martinez .......... Elizabeth McClendon .......... 706-650-2715 .......... cmclendon1@msn.com
Atlanta .......... Jack Persad .......... 404-766-9203 or home: 404-767-8796
Illinois
St. Jacob .......... Dorthy Muniz .......... 211 Jacob Court, 30967
Naperville .......... Mike Maki .......... mmmaki@chapterhouse.com
Louisiana
Shreveport .......... Erin Pas .......... 318-797-2764
Massachusetts
Martha .......... Locetta Minoa .......... 4 Lowe Drive, 01930
Maryland
Baltimore .......... Elaine Gaine .......... 410-477-9445
Mississippi
Cleveland .......... K. Lance Jackson .......... 404-846-4603 .......... jackson@ecinfo.com
New Jersey
Lakehurst .......... Matiin Leber/BP .......... 732-657-0694
W. Orange .......... Hannah Lisa Reade .......... 973-736-1253
New York
Brooklyn .......... Peg Schofield/BP .......... 718-584-3392
Bronx .......... 646-409-0227
Brooklyn .......... Miriam Weiss .......... 718-232-2681 .......... mweiss@esbcs.com
Brooklyn .......... John DeLube/NPF VP .......... 631-286-4919 .......... mloeb@aol.com
Brooklyn .......... Sandra Feldstein .......... 514-693-1157 .......... heinbock@earthlink.net
New York .......... Barry Katz .......... 718-723-3693
New York .......... Linda Tafel .......... 718-425-4917
Ohio
Lyndhurst .......... Roz Cameron .......... 714-473-1336
Perrysburg .......... Dorothy Strayer .......... 419-374-5976
Oregon
Eugene .......... Steve Shapino/Alternate therapy .......... 541-686-5583 .......... shapino@oregon.oregon.edu
Pennsylvania
King of Prussia .......... Gregory Davis .......... 610-337-8293
Little Meadow .......... Sharon Hickey .......... 717-623-2502
Warren .......... Betty Malhot .......... 717-726-3632 .......... pauljm@kinzua.net
Texas
San Antonio .......... Dorcy Coker/BP .......... 210-282-6632
Virginia
Richmond .......... Nicholas Moskovitz .......... 804-276-0853
Petersburg .......... Lynne Stanley .......... 804-236-1969
West Virginia
Riverton .......... Daniel & Sandra Perry .......... 304-645-6637 .......... sperry57@hotmail.com
Wisconsin
West Bend .......... Peggy Proehrer .......... 414-629-9101
Wyoming
Cheyenne .......... Brenda Schutz .......... 307-632-2901 .......... gbshutz11@bills.com
Australia
Boonah .......... Julian Chan .......... 07-3916-1787 .......... jchan@ca.com.au
Canada
Toronto .......... Dan Goodwilli/Gdp Leader .......... 416-488-0453
England
Greater Manchester .......... Carolyn Blythe .......... 0161-334-6100 .......... carolynblythe@campurseve.com
London .......... P. Vonk & C, 88 St George Rd, SE 21, London, EN 6-8 ok (stamped self-addressed envelope)
South Yorkshire .......... Mrs. J. Moncini .......... 01226 748 316 .......... jmoncini@btinternet.com
Israel
Haifa .......... Victor Lefkowitz .......... 972-3-482-3439 .......... victorl@actcom.co.il
Italy
Rome .......... Anna Lisa Riccardi .......... ali246@yahoo.it
New Zealand
Nelson .......... Gloria Romano .......... P.O. Box 1051, Nelson, New Zealand

Here’s your key...

to the best information available.

Unlock it today.

Contribute to the International Pemphigus Foundation and receive the IPF Quarterly. It has the latest information on pemphigus research, plus valuable, pertinent and accurate information for those who live with pemphigus/pemphigoid and their caregivers. The medical information in Quarterly is reviewed by a member of the Foundation’s Medical Advisory Board, so you can be confident of its accuracy. And best of all, your contribution not only covers the cost of your newsletter, but also goes to support the research that could eventually cure pemphigus & pemphigoid. Donate today!

*A star next to your name on your mailing label means a year has gone by since your subscription renewal. If you would still like to receive this newsletter, please send in the form below if we don’t hear from you, we’ll assume you no longer wish to receive it.

Copy or cut out this contribution form, print clearly, and return with your donation to:

International Pemphigus Foundation
The Atrium Plaza, Suite 203 . 828 San Pablo Avenue . Albany, CA 94706

[Checkboxes and fields for different donation options]

[Fields for payment instructions]

Expiration date: MO.:_______ VR.:_______

Signature (REQUIRED):

Print name: ___________________________ Date: ___________________________

City: ___________________________ State/Province: ___________________________

Postal Code: ___________________________ Telephone: ___________________________
2003 IPF Meeting Slated for Fort Lauderdale, Florida

Every year the Foundation holds its Annual Patient/Doctor Meeting. This year we held that meeting in New York, as reported in this issue. Next year, we are looking to have our meeting in Fort Lauderdale, Florida possibly in late October or early November, 2003. We are looking for people who might want to help us put this meeting together.

As the Foundation's office is located in California, it is difficult for us to put on a meeting without having someone in the local area to help. This is a terrific opportunity for the patients, their family and friends in the Southeast to have a chance to hear experts on pemphigus/pemphigoid, to ask questions and get answers first hand. There is also the opportunity to meet others in the area who you can continue to communicate with after the meeting is over.

It is amazing how positive these meetings can be. Meeting and talking with others who know what you want and what you need, and who are going through the same things you are, is an uplifting experience.

Most of the people who have been to our meetings over the years have found them to be interesting, informative, and worth attending. If you would like to help the Foundation put together a sixth annual meeting in Ft. Lauderdale, Florida, please contact us for further information.