Segall remains Executive Director

Barish named new NPF President

Stepping up to help shoulder the work-load borne by founder Janet Segall since 1994, Jean Barish, a patent attorney from New York City, was voted President of the National Pemphigus Foundation by the Board of Directors on April 1, 1999.

"It just got to be too big a job for one person" said Segall, who will remain Executive Director. "The Foundation has grown so much since I started it in 1994. Now I can concentrate on the growing list of tasks that will allow us to reach even more patients and provide even more education and support."

"Janet's contribution to the fight against pemphigus cannot be measured nor accurately described," said Barish, who has been on the Board since 1997. "To have the heart to see the suffering, then the vision to see what had to be done is one thing, but to actually scratch and claw to make that vision into a reality with little more than her bare hands is nothing short of heroic. We all owe Janet a huge debt of gratitude."

Barish sees increasing the Foundation's visibility as an important step toward finding as many sufferers as possible. She wants to continue the educational and support activities already in place and expand fund raising efforts.

"Most importantly, the Board is here to provide all the support possible to help the Foundation grow and develop into a voice for the pemphigus community," she said. "We will look for more substantial sources of donations from business and funding organizations."

Barish lives in New York City. She works at Warner-Lambert, a worldwide producer of pharmaceuticals, in New Jersey. She is a member of several other boards including the New York Epilepsy Institute.

Joan DeLucie of New York moves up to Vice President. Lee Heins of Costa Mesa, California pulls double duty as Treasurer, and West Coast Fundraising Chairperson.

Carolyn Rodis J.D., M.A. from Harwood, Maryland remains Secretary. Fund-raising

CPA-SDR group lobbies Congress

Each year member organizations of the Coalition for Patient Advocacy and Skin Disease Research (CPA-SDR) gather in Washington D.C. to meet with representatives of the National Institute of Arthritis, Muscular, Skeletal and Skin Diseases (NIAMS). For two days members discuss common goals and meets with Congressional leaders to support funding for skin disease research by the National Institutes of Health, of which NIAMS is a section. Executive Director Janet Segall represented the CPA-SDR at the Conference March 9 and 10. Dr. Steve Katz, director of NIAMS, welcomed delegates during opening ceremonies.

"Our meeting with Dr. Katz, was very interesting," reported Segall, "Because of the 15% increase in the 1998 NIH budget last year, $3.2 million in research money went directly to PV and PF research. This is of a total $273.9 million. NIAMS also allocates money toward more general clinical research. The CPA-SDR is advocating an additional 15% increase in the NIH budget for the year 2000, a 15% increase in the NIAMS budget, and a doubling of the funding over the next five years.

"Unfortunately, the President's new budget asks for only a 2.9% increase for the year 2000. This reduction in funding to the NIH will be a serious problem for researchers in the coming years," said Segall.

Later representatives met with physicians from the Society of Investigative Dermatology (SID). They discussed the trip the next day to various congressional offices to encourage

Med Board meets during AAD

Elizabeth Dole was the guest speaker at the American Academy of Dermatologists' annual membership meeting March 19 - 23, 1999 in New Orleans. Mrs. Dole thanked the CPA-SDR for its "unadventured efforts" to bring attention to skin diseases.

The annual meeting brings together dermatologists from around the world and presents the NPF with an opportunity to disseminate information to those attending. David Rosen from New Orleans joined Executive Director Janet Segall to shake hands and answer questions. Many new physicians, mainly from overseas, stopped by the information booth to report that pemphigus may not be as rare as the statistics suggest.

Concurrently, the Medical Advisory Board of the NPF had its first meeting in New Orleans. Physicians attending the MAB meeting included Grant Anhalt.
Together we can make a difference

On behalf of the Board of Directors of the National Pemphigus Foundation, I am pleased to announce our unanimous decision to fund the positions of Executive Director and Communications Director. Until recently these have been unpaid, volunteer positions. Janet Segall has been appointed to the full-time position of Executive Director and Sal Capo has been appointed to the part-time position of Communications Director. As a result, Janet resigned from the Board of Directors effective April 1.

Four years ago Janet started the Foundation from a small office in her home. Since then she has worked tirelessly to create an outstanding organization of which we can all be proud. We now have the support of hundreds of people worldwide, a first class newsletter and website, an active online support network with over one hundred participants, and a world-renowned group of physicians on our Medical Advisory Board. Last August we held our first meeting in Chicago, “First Contact,” a one-day meeting that was a rousing success. Our second annual meeting will be held in New York City on July 31 and August 1. Additionally, we have formed alliances with several coalitions that are focusing on broad policy issues such as research and health-care.

Most important we have created a community that cares about pemphigus and wants to deal with the issues related to this disease. Each day the Foundation is contacted by someone who is searching for information or support for themselves, a family member or a friend. We have reached many dermatologists who serve as a referral service around the globe. We are reaching out to the business community for support. And we are sharing and helping each other in our ongoing battle with pemphigus.

The appointment of a salaried staff elevates the Foundation to a new level and demonstrates our commitment to serving the pemphigus community. We believe we have now laid the groundwork for an organization that will be able to meet our needs for support, education and public awareness.

As Executive Director Janet will continue to guide the Foundation in its growth, and supervise all of its activities, including networking, education, fund-raising, public-relations, and community outreach. As Communications Director Sal will continue to maintain the website he created, produce The National Pemphigus Foundation Quarterly and, with Sandra Frank, manage our online support group.

We are confident that Janet and Sal have the talent, skill and energy to help the Foundation reach its goal of helping people deal with pemphigus, and ultimately, finding a cure for this disease. We congratulate all of you for bringing the Foundation to this crossroads and we encourage you to wish our new staff great success.

Finally, we ask all of you for your continued support and encouragement. The success of the Foundation depends on you. Together we can make a difference.

Jean B. Barish
President, Board of Directors
The National Pemphigus Foundation
Results of survey on drugs used to treat pemphigus

By Rebecca Berman, Janet Segall and Jean-Claude Bystryn, M.D. from The National Pemphigus Foundation and The Ronald O. Perelman Department of Dermatology, New York University School of Medicine, New York, NY
February 17, 1999

As many of you know, we recently conducted a survey of persons with pemphigus to find out 1) which treatments were most commonly used, 2) which appeared to be the most effective, and 3) which were most often associated with side effects.

The survey was conducted by means of a questionnaire enclosed in the Fall 1998 issue of the National Pemphigus Foundation newsletter, the Quarterly. The questionnaire was also sent to all individuals who responded to a notice on the NPF website.

A total of 110 responses were received. This number is impressive, taking into account the rarity of pemphigus. We thank all participants for their collaboration. The results of the survey have been analyzed and a summary of the findings follows.

The questionnaire was focused on commonly recommended therapies. These were topical, intralesional and systemic steroids, cytotoxic drugs (Imuran, Cytoxan, Cyclosporin and Methotrexate) and antiinflammatory agents (Dapsone and Tetracycline).

Most respondents had tried multiple agents.

Overall, 8% of respondents tried one agent, 24% tried two, 28% tried three, 17% tried four, and 22% tried five or more of the drugs listed above.

Currently, 33% of patients are using one medication, 42% are using two medications, 17% are using three medications, and 10% of patients are using four or more medications.

<table>
<thead>
<tr>
<th>NUMBER OF DRUGS TRIED (%)</th>
<th>8</th>
<th>24</th>
<th>28</th>
<th>17</th>
<th>22</th>
</tr>
</thead>
<tbody>
<tr>
<td>NUMBER OF DRUGS USING NOW (%)</td>
<td>33</td>
<td>42</td>
<td>17</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

The agents used most commonly for the treatment of pemphigus were systemic steroids, topical steroids and Imuran, which were tried by 78%, 72% and 64% of respondents respectively. The least commonly used agents were Cyclosporin, Tetracycline and Methotrexate, which were tried by 8%, 13% and 14% of people respectively.

The drugs that appeared to be the most beneficial from the respondents' perspectives were: systemic steroids, Imuran and topical steroids, which were described as helpful by 100%, 62% and 60% of patients who used the drugs.

The least beneficial drugs seemed to be Tetracycline, Dapsone, and Methotrexate, whose use was discontinued because "it did not work" by 43%, 24% and 20% of patients treated with the drugs.

The drugs associated most often with side effects severe enough for treatment with that drug to be terminated were Cytoxan, Methotrexate and Imuran, which were discontinued by 38%, 33%, and 27% of users. To estimate the apparent relative effectiveness of the various drugs used to treat pemphigus, we calculated the ratio of respondents who believed the drug was useful to those who thought it did not work.

On that basis, the most effective drug was systemic steroids, with a ratio of 25. The ranking of the other drugs, based on their relative perceived effectiveness, were Imuran (ratio 5.1), topical steroids (ratio 5), Cytoxan (ratio 3.5), intralesional steroids (ratio 3.3), Methotrexate (ratio 2), Dapsone (ratio 1.4), Cyclosporin (ratio 1.3), and Tetracycline (ratio 1.1).

This survey was very helpful in collecting data from a large number of patients suffering from pemphigus. However, it must be kept in mind that the reliability of the data is subject to question. One problem is that patients' evaluations of response to treatment is subjective, that in many cases treatment was given over a number of years and that memory of earlier treatment may not be completely accurate; and lastly, that several agents may be used concurrently so that the determination of which was effective is difficult.

We again wish to thank all respondents for their time and effort. We hope you will be able to respond to additional questionnaires in the future.
Dallas (New!)

First meeting is May 22 at the Columbia Medical Center in Arlington, Texas. Dr. Amit Pandya of UT Southwestern Medical Center will be our guest speaker.

If you want to take part, please call:

Contact: Angela Vickers
817-557-9642

Los Angeles
By Carol Goren

The Los Angeles Chapter met on February 7, 1999 with 31 members in attendance, which included nine new members. Lee Heins, Fund Raiser Chairperson, reported that the 1998 fund raiser raised $40,000 nationally. The Los Angeles Chapter raised $9,000. Janet Segall attended the meeting, shared the history of the Foundation and discussed the current research projects.

She indicated there are three doctors located in Los Angeles, with a large Pemphigus base: Dr. Levins, Dr. Kaplan and Dr. Gusrevitch. Members asked Janet questions regarding treatments and she made suggestions on ways to help reduce side effects to the drug therapy. General business was discussed.

The next meeting will be held in May. The members indicated the areas they would be interested in having speakers: nutritionists, pharmacists, psychologists.

Contact: Marcia Kassan
Phone: 818-340-7180
Email: enter@loop.com

New York
By Joan DeLucie

On January 21, 1999, twenty-one members and guests attended the New York support group meeting at New York University Medical Center.

Dr. Joyce Rico opened the meeting by introducing Ben Bronstein, M.D., and President of Peptimmune. Dr. Rico explained that Dr. Bronstein was joining us to collect blood samples from PV volunteers so his company can continue its pemphigus research project. Dr. Bronstein gave a brief scientific summary of the work Peptimmune is doing and explained the need for more blood donations. He outlined what they are hoping to develop a therapeutic vaccine for pemphigus vulgaris. Following the summary, Dr. Rico, Dr. Bystryn and Dr. Bronstein graciously participated in a question and answer session.

By Matt Koenig

On April 15, 1999, about 25 members and guests attended the New York support meeting at New York University Medical Center. Joan DeLucie updated everyone regarding the preparation for our hosting of the Summer Conference.

She also announced the addition of three new members for the Heart2Heart, contacts section of the newsletter: Peg Shroder, Sandra Feldstein, and Cynthia Gordon. Their experience covers bullous pemphigoid, pemphigus vulgaris, and pemphigus foliaceus.

The group welcomed Dr. David Sirois, who established and now directs the Division of Oral Medicine at the New Jersey Dental School. Dr. Sirois and the Oral Medicine staff provide diagnosis and treatment for over 200 patients each year with chronic oral ulcerative and bullous disorders. He also maintains an active basic and clinical research program, and has published widely on oral mucosal ulcerative disorders.

In his presentation, Dr. Sirois showed the progression of PV and its related disorders, both at the visible and cellular levels. He reviewed various courses of treatment, and discussed their capabilities and side-effects. This was followed by a lively question and answer session.

Dr. Sirois also distributed a survey re-
The National Pemphigus Foundation

SUMMER 1999

LA CONTRIBUTES $9,000... NY GIVES BLOOD TO PEPTIMMUNE

Regarding early symptoms to the group, in order to get a better understanding of which medical specialists would be more involved at the early stages of these disorders. In his surveys performed to date, about three-quarters of the respondents reported that symptoms began in the mouth.

We are all looking forward to the Second Annual NPF conference! As your hosts, we want to welcome you to New York City, so please feel free to contact us if you need local information or special arrangements prior to your arrival!

Contact: Joan DeLucie
9 Mehan Lane
Dix Hills, NY 11746
Phone: (516) 586-6910
Email: jdelucie@aol.com

Contact: Matt Koenig
88 East Valley Stream Blvd.
Valley Stream, NY 11580
Phone: (516) 825-4594
Email: mattkoe@aol.com

San Francisco
By Sal Capo

Forty-four members and family were hosted by Dr. Sergei Grando and staff at U.C. Davis near Sacramento for lunch and a lecture about Dr. Grando’s current research project, which was featured in the last issue of the NPF Quarterly.

While we munched on the box lunches provided by the good Doctor, he and his associate, Vu Nguyen ran through the slides which will be used later in a presentation to the Society for Investigative Dermatology in Chicago.

Through the use of new technology, and mice born without Desmoglein 1 and 3 (thought to play a pivotal role in pemphigus), Dr. Grando’s team believes they have determined that other factors are at work. They also believe they are on the path to isolating one or more of those factors.

Following an enthusiastic and detailed explanation of what steps have been taken so far, volunteers were recruited to donate blood to further this research. Eighteen men and women stepped forward gladly. As blood was being drawn, Dr. Grando fielded questions from the audience.

A bright and sunny day was made all the more pleasant by getting together with those we had not seen in some time, and the special guests, Sonia Tramel from Long Beach and Maureen DeViso from San Diego.

No plans have been made concerning another meeting.

Contact: Janet Segall
Phone: 510-527-4970
Email: pvnws@aol.com

Toronto
By Dan Goodwill

The Toronto support group held its last meeting on March 7. It was encouraging to observe the progress that has been made in the health of each of the members, despite setbacks along the way. One member of the group is currently off Prednisone, and is on Imuran only. Three members of the group are on Prednisone and Cellcept and all are showing improvement. One member is on Prednisone only and her dosage has dropped below 10 mg a day.

The group requested that Dr. Daniel Sauder, Toronto, foremost expert on pemphigus, attend the next meeting to conduct a question and answer session and talk about the research that he is doing. The next meeting is scheduled for May 16. Dr. Sauder indicated that he will be out of the country that date but he will try to arrange an evening session at Sunnybrook Hospital in one of the conference rooms. The date of this particular meeting will be communicated to the Toronto support group, once it has been determined.

Contact: Dan Goodwill
105 Hillhurst Blvd.
Toronto, Ontario, M5N 1N7 Canada
Phone: 416-488-0453
Email: danxgail@ican.net

Baltimore
Contact: Erica Byrne
4610 Learned Sage
Elicott City, MD 21042
Phone: 410-964-1099
Email: byrneete@erols.com

Houston

Contact: Richard M. Schwartz
5231 Kinglet St.
Houston, TX 77035
(H) 713-723-5647
(W) 713-721-1178
Fax: 713-726-0286
Email: richardm@hal-pc.org

Midwest

Contact: Arlene Strauss
514 Inverary Lane
Deerfield, IL 60015
Phone: 847-808-9188
Email: ChicagoPV@webtv.net

Philadelphia

Contact: Barbara Sipe
Phone: 215-662-6446

The NPF Website
Sal Capo, Webmaster

The NPF website contains a large selection of articles from previous issues of the newsletter on a range of topics. Other articles are added when available between issues, so check the website often.

Also offered is a large selection of links to sites of interest to those living with pemphigus and their caregivers.

Please visit www.pemphigus.org and please let us know how we might improve our site.

Online discussion
Sandra Frank & Sal Capo, Managers

The National Pemphigus Foundation Online support group is open to everyone interested in pemphigus.

To join the list send a blank message to discussion@pemphigus.org. No other information is required. Your email address will then be added automatically.
Facing a chronic disease, especially pemphigus, is a challenge no one can anticipate. The Rosalynn Carter Institute, which specializes in research into methods for handling chronic and life-threatening diseases, has studied the emotional patterns patients can expect when adjusting to the changes disease makes in their lives. These often unpleasant changes are rarely discussed, but both the patient and caregivers should be aware of them, knowing that they are both typical and necessary parts of the healing process. All concerned are grieving over the loss of the life they thought they would have, and that takes a toll.

**Loss of control.** Plans for the future are necessarily changed. Medications, especially Prednisone, cause changes that are initially unpredictable. Very often the side effects are not clearly explained, making the physical and mental changes even more frightening.

**Changing self image.** Social realities change when a caregiver can’t work or socialize as before. Pemphigus causes overt changes in physical appearance for many people, leaving them unsure about how they will be received.

“I know I was very concerned about my appearance,” Carrie Twitchel admits. “I had many lesions on my face, eyes, ears and neck. I was not able to use makeup so they (her husband and three children) were all reassuring me that it didn’t look that bad. But, when Sarah, 8, said sweetly to me one day, ‘maybe you should wear a little makeup mom, my friends are starting to ask me if you have the chicken pox’, I knew I wasn’t looking too great.”

**Dependency.** For most people, asking for help is difficult. Not being able to predict how long or to what degree one will need help makes accepting assistance more difficult. The more independent one was, the harder the change will be. Many people feel guilty about the fact that they can no longer fill their accustomed roles in life, blaming themselves and often feeling self pity. Some respond by trying to do too much, others by giving up and doing nothing at all.

**Stigma.** Explaining the disease to friends and co-workers can be difficult, and often they will respond in ways that make the patient uncomfortable. The learning curve for those outside the family is unpredictable, and many people are afraid of anything they don’t understand.

**Abandonment.** While pemphigus rarely requires the sort of intimate attentions which are part of other chronic diseases (being bedridden, profound memory loss or dementia), there are still elements which would be a strain on friends and family. It’s easy to see that one would be concerned that those people will become tired of the work involved and pull away.

**Anger.** As noted, having pemphigus will change the lives of the patient in significant and unpredictable ways. Anger is a normal response; anger at the disease, at the changes and at the fate which chose this challenge.

“The worst was when I had absolutely no patience around the house, when I was on high doses of Prednisone,” confirms Susan Maizer, “I lashed out everywhere.”

**Suppressing the anger can lead to emotional outbreaks at inappropriate times, often confusing even to the person who explodes over something which seems trivial. It can also confuse caregivers, leaving them feeling as if they have no control. It’s normal to want to control anger, but ignoring it can lead to situations which are damaging to all concerned.**

**Isolation.** Life has changed and many people pull back from things they formerly enjoyed because they no longer feel capable to do them in the same way. There are also things that they have to admit they can no longer do, at least for now. The fear that this chipping away at life will leave them with nothing can be paralyzing.

**Medication narcotics the physical problems for some people. Prednisone can cause mood swings and impaired judgement, leaving a patient unwilling to make plans because he does not know if he will feel able to handle the event.**

Carrie concurs, “Support, understanding, love and kindness were also key. I had to drop out of many commitments when I was on 80 mgs of Prednisone. I couldn’t focus well, couldn’t handle large groups of people, or do two things at once. Also I had terrible memory losses. My children and husband had to remind me of everything.”

Both patient and caregiver should make time to talk over these issues. The caregiver experiences a mirror version of these fears, and would be wise to admit them as well. A frank discussion of the emotional aspects can relieve a lot of tension and guilt on both sides. This is the double-bind which can be so emotionally dangerous. If the patient feels ‘I shouldn’t feel angry... look at all they’re doing’ or (for the caregiver) ‘I shouldn’t feel angry... look at all he’s going through’ then neither is being emotionally honest and this can poison their interactions. Anger suppressed leads to resentment or depression, neither of which are healthy additions to the situation.

Susan says it well: “The most important thing I need always is, for him and my other family members to just listen when I have to talk about my pemphigus and not make judgements or tell me not to worry. I always find I work it out somehow, myself, after I vent a little or a lot.”

Education can relieve a great deal of stress for all concerned. The patient and the caregiver should make sure they are partners in this aspect of their lives. Patients should keep caregivers up to date on the information they receive from doctors or from their own research. Caregivers should do the same. With the vast amount of information available, it’s easy to overload or lose perspective. Two people sharing the load make it less likely that one is carrying the entire emotional or practical burden. It will also help sort out which information is useful and which is speculative. Often it takes another person to ask the question ‘where did you get that information? What supporting evidence is there?’ Brainstorming is better than brooding.

The patient is the one ultimately responsible for the care they receive. Caregivers will be best able to assist if they are clear about what is expected. It’s typical for a caregiver to try to do too much, often out of a feeling of guilt about their own health. It’s normal to want to take the pain from those we love, and many caregivers feel oppressed by the fact that they can’t
gus is a disease which requires us to test our own limits and adjust accordingly.

Support groups are an important resource which cannot be overemphasized. The NPF group members all praise the strength and assistance they find in meeting with people who share the same challenges. Sharing doubles the joy and cuts the sorrow in half.

"The (online support) group, of course, helps relieve some of this anxiety, too. My husband takes a great interest in all the postings I get and we discuss them freely," observed Susan Maizner.

Members find groups to be a place where they discuss the day-by-day occurrences, the details and the challenges. Face-to-face meetings bring life to the fact that the patient and family are not alone. The online support group allows almost instant interaction, at any comfort level. There's also great strength in knowing what others have gone through and how they handled the various aspects of treatment. Caregivers should also involve themselves in these forums, (as many do). Everyone involved can learn from the exchange. New patients learn what they can expect, while veterans can keep up to date with the changing face of recovery.

Caregivers have an independent challenge, one which they themselves can overlook. Studies report that the burnout rate for family caregivers is over 50%. Much of this can be attributed to the lack of definition in the roles, along with a lack of outside support. It can be hard for a husband, wife, parent or child to admit that they can't do all that is required. It can be hard to even see beyond the current state of life to realize that there are options. As more and more families encounter these situations, resources are being developed to focus on the needs of the caregiver as well as the care receiver.

Presently, most of the support groups, books and studies focus on elder care and diseases with a higher profile than pemphigus. This is not to say that these resources do not contain useful information, but that research is required to sort out what is pertinent to the particular circumstance. Some of the basic points which are applicable to all caregiving:

- It is critical to take charge of the role required, defining it for all concerned. As the patient should be clear on what they expect, the caregiver should also be clear on what they can do. Getting help, from whatever sources available, is something that should not be delayed. Make sure all members of the family have something to do, so that the entire burden does not fall on one person. Make sure the doctors and other medical professionals know the primary caregiver and are responsive to questions from that source.

- Education is the best defense against the helpless feeling that comes from having a loved one ill. Many pemphigus patients find the resources and support, which is so critical, through the efforts of friends and family who took the time to do the work.

- While there is no way to control stress entirely, caregivers should take the time to be good to themselves. It is not selfish to need time alone or indulge in an occasional treat. Every resource on caregiving makes this point repeatedly: the caregiver will not do anyone good if they collapse under the strain. By taking time to refresh, the caregiver collects more strength for the role they are playing, as well as making themselves people that are refreshing for the patient to encounter. Pemphigus changes life for more than the patient, and it's important to recognize that not all adjustments are desirable. Giving up something that feeds the soul because the patient can no longer enjoy it will only lead to resentment.

- Depression is unfortunately a common result when caregivers try to do too much and don't give themselves credit for all they have done. Since the majority of caregivers are women, and women are sta-

Continued on page 13
Exploring the 'wildfire' world of pemphigus foliaceus

By Luis A. Diaz, M.D.
Professor and Chairman
Department of Dermatology
Medical College of Wisconsin
Milwaukee, Wisconsin

I am extremely pleased to join the Medical Advisory Board of the National Pemphigus Foundation. The contributions made by organizations such as the NPF are invaluable to the patients afflicted with the diseases as well as to the medical community.

Pemphigus foliaceous (PF) one of the major clinical variants of pemphigus, is characterized by superficial blisters and anti-epidermal autoantibodies. The epidermal antigen with which PF autoantibodies react is a desmosomal protein designated desmoglein 1 (dsg1). There are two forms of PF: an sporadic form which has worldwide distribution, and an endemic form, which has only been observed in certain rural areas of Brazil, Columbia and Tunisia. In Brazil, the endemic form of PF is known as Fogo. The name FS translates to "wildfire" in Portuguese and refers to the burning sensation that the patients feel upon sunlight exposure.

The endemic and non-endemic forms of PF exhibit indistinguishable clinical, histological and immunological characteristics, i.e., superficial blistering caused by autoantibody-mediated cell-cell detachment within the outer layers of the epidermis. In summary, FS is a human autoimmune disease mediated by pathogenic autoantibodies that are produced by immunogenetically predisposed individuals living in certain rural areas of Brazil. The results of epidemiological studies of FS point toward a, as yet unknown environmental antigen as the trigger of the disease. The antigenic mimicry model predicts that the dsg1 protein harbors T and/or B cell epitopes that are shared with the environmental agent that precipitates the disease.

We have recently identified a new FS focus with a unique set of environmental, genetic and cultural characteristics that make it an ideal population on which to focus our investigations on the epidemiology and etiology of this disease. This community, the Limao Verde Indian Reservation in central Brazil, is composed of approximately 1000 members of the Terena Indian Tribe. Geographic, familial and temporal clustering patterns have been detected among the 31 FS cases on this reservation, and the disease was found to be associated with HLA-DRB180404, 1402 & 1406 haplotypes (RR=14).

In contrast, other Terena reservations in the region show very few or no documented FS cases. We are currently carrying out a series of case control epidemiological studies designed to further define genetic and environmental risk factors of the disease. Controls from three populations will be studied: unaffected family members of FS patients, unrelated individuals from Limao Verde, and unaffected Terena Indians from a neighboring reservation.

Other ongoing studies include the following: a) a prospective sero-epidemiological survey of this population using indirect immunofluorescence and an ELISA assay with recombinant dsg1; and b) investigations of the cellular and molecular regulatory mechanisms involved in the pathogenic autoimmune response in these patients. Information obtained from these studies would be relevant in understanding the onset and development of FS and other human autoimmune diseases.
Strolling through Peptimmune’s lab

By Matt Koenig

In mid-January the New York support group was pleased to host Mr. Ben Bronstein, CEO of Peptimmune, who gave a presentation and collected blood samples from about 12 volunteers. I asked if I could tour their facilities in Cambridge Massachusetts the following week, and he agreed. The presentation and my visit showed me some fascinating information about PV and its biology, which I thought should be shared. Here’s my best attempt at interpreting what I heard.

Key terms: Proteins are complex molecules that are produced in living cells, and are used by them to provide structure and function for the cells and their environment. Proteins are built up from hundreds of smaller molecules called Amino Acids, which are strung together in a sequence that is determined by the cell’s DNA. A fragment of a protein consists of a smaller portion of this chain of amino acids, and is called a peptide.

The premise: Well, it turns out some of the cells in specific areas of our skin (called mucous membranes) manufacture a protein called desmoglein-3. This is a protein which is attached to the outside of these cells and binds them together. It is made up of a chain of approximately 600 amino acids, all in a specific order. In PV patients, some of their white blood cells have been programmed to eat a portion of the desmoglein-3 protein, because for some reason, our immune system has labeled a portion of this protein to be a foreign substance (like a virus, bacteria, or even a speck of dirt). As a result, the desmoglein-3 bridge between cells breaks apart, and the cells begin to drift. If enough cells drift away, they form a blister, or lesion. We all know that part.

Who done it? Now, our friends at Peptimmune have been able to exactly define the desmoglein-3 protein. They have utilized a method similar to DNA analysis in police investigations. The chemical breakdown of desmoglein-3 yields a whole bunch of peptides, one of which is probably the flag that sets off the immune response. Their strategy is to determine which peptide is the culprit. They are doing this by feeding the identified peptides to our volunteer white blood cells. How do they know which peptide is guilty? To paraphrase “Star Trek,” “what do you get when you feed a white cell? A fat white cell? No, lots of little white cells, all with the same PV characteristic. Peptimmune can observe the growth and isolate the culprit. This is the stage they have reached. By the way, if you wondered why PV symptoms seem to get worse at an ever-increasing rate if ignored over time, it has to do with the doubling rate of growth of your voracious PV-sensitized white cells.

Needle in a Haystack. The interesting thing about our blood is, only about 1 in 100,000 white blood cells actually is programmed to respond to the peptide in desmoglein 3, and not everyone’s blood will generate an immune response. This may depend on each individual’s current level of activity. For example, an individual who needs 20 mg of Prednisone each day to remain free of PV symptoms will have a more active PV immune response than an individual who only needs to take 5 mg a day. These 2 problems taken together will account for the long time that it takes to identify the peptide culprit. Still, it is not impossible, only a matter of time. The folks at Peptimmune are deep into this part of the process right now.

The theory: Even if they find it, so what? Here comes the leap of faith. There is a documented immune response that goes like this: if there is a certain substance that your immune system responds to (like a virus or the peptide in desmoglein-3), you can suppress that immune response if you put an excess amount of that substance in your immune system and body functions continue to work correctly, or at least as well as they did before PV.

What’s next? So, once the peptide culprit is found, then what happens? Tests, tests, and more tests. None of us should be surprised if Peptimmune asks for more blood donations over the next couple of years in order to verify their findings. Once verified and proven harmless to test animals, they will submit their findings to governmental agencies in a bid to begin tests on people. That’s where we come in, through the participation of our doctors.

What can we do? I asked the Peptimmune people that question and they suggested that we mobilize, organize, and vocalize. Peptimmune relies on venture capital for their research. This means that they don’t need us to raise money for them but they do need to coordinate with us to expedite the governmental approval phase for them when the time comes. That means that we should tell our doctors and government representatives about PV, about Peptimmune, and about our need to get this process moving as quickly as possible. Part of this includes showing up at the right conventions, meetings and government sessions. This is where supporting Janet and the Foundation really comes into play. We need to tell doctors, senators, congressmen, and governmental agencies like the FDA and the NIH that we exist, that Peptimmune exists, and that we want to get any obstacles out of the way. Janet has already been doing this, and we need to get on board with her and make sure everyone knows that she is not the only one who has PV.
Foods that eat you?
Some nutrients have compositions like the drugs that cause pemphigus

Dr. Sarah Brenner and her associate Dr. Ethel Tur, both of the Tel Aviv Sourasky Medical Center of Tel Aviv University in Israel, have recently published a paper entitled, "Diet and pemphigus, in pursuit of exogenous factors in pemphigus and fogo selvagem." The article appeared in the November issue of The Archives of Dermatology.

While medical science does not yet know the cause of pemphigus, it has been established that certain drugs can cause the disease in humans. Those drugs include penicilamine, captopril and ritapimcin.

"Since some nutrients have chemical compositions similar to these known causative drugs, these nutrients may act similarly and therefore nutritional factors should also be suspected," state the authors. "As when drugs are involved, elimination of the inciting ingredients may be crucial for management of the disease."

The foods in question contain one or more of four ingredients: thiol, isothiocyanates, phenols or tannins.

The artificial sweetener aspartame is a phenolic and common in many food additives, such as preservatives, colorings, flavorings, sodium benzoate, tartarazine (Yellow dye No. 5), vanillin, eugenol, caffeic acid, and vitamins C and E. Phenol is in the cinnamon tree and cinnamon acid can be found in fruit juices (apple, grape, orange, pineapple and tomato) and flavorings for sweets and foods.

Another phenol is pinene, used in baked goods, beverages, condiments, candies and ice cream. It is in tomatoes, potatoes, mangos and bananas. Black pepper is 5% to 9% piperine. Wood used for barbecuing and adding the smoked flavor to foods contain phenols, as does the milk and milk products produced when cows consume phenol laced feed such as cottonseed.

Tannins: Tannins have a wide range of effects on human biology, including interactions with drugs and a cytotoxic effect on peripheral blood lymphocytes. There is also evidence suggesting tannins inhibit copper utilization, (the pemphigus inducer penicillamine chelates copper also). Common sources of tannin are kola nuts, black walnut, raspberry, cherry, cranberry, blackberry, avocado, banana, apple, mango, pear, persimmon, eggplant and grape skins, coffee and cocoa seeds, ginger, ginseng, garlic, rosemary, arrowroot, ajowan, coriander, cumin, black pepper, yucca, cassava leaves, guarana, and the stems of vanillin.

Beer, wine and soft drinks have tannin added. Some teas contain tannins, as do carob shells and the addictive betel nut which is widely used outside the United States.

According to the article, "The incidence of fogo selvagem (the South American form of pemphigus), drops as populations move into urban areas with chlorinated water supplies."

Racquel is smiling now

During the AAD meeting in New Orleans, Janet met with Racquel McKinney and her mother Debbie who live in New Orleans. Racquel is 10 years old.

"We had a terrific afternoon," said Janet. "We took a trip to McDonald's for lunch and toured St. Charles Place which consists of beautiful homes going back hundreds of years. Racquel has been a real trooper in her fight against a severe case of PV for a couple of years now. We all wish her the best of luck."

Jean Barish elected

Chairperson for the East Coast is Robert Mufson of Boca Raton, Florida. Vice President of Scientific Affairs is Dr. Grant Anhalt of Baltimore, Maryland. Jonathan Segall, former Treasurer, has resigned from the Board.

Med Board at AAD in New Orleans

Each of the doctors voiced support for the Foundation. The Medical Board voted unanimously to attempt to cosponsor a pemphigus symposium in conjunction with NIH sometime next year.

Dr. Sarah Brenner of Israel (See article on this page) reported that among Eastern European Jews in Israel, the incidence of PV is documented as 3 in 100,000 patients per year.

Put your heart into it

Membership is growing, especially in the Florida area. Volunteers are needed to talk or email fellow patients about pemphigus. If you would like to be listed in Heart2Heart, please contact the Foundation.
THANK YOU!

The generosity demonstrated by those listed below to this otherwise largely ignored disease provides the fuel for the numerous projects and countless acts of education, support and comfort which would not otherwise be possible. Thank you simply does not say nearly enough.

Grand Benefactors $5,000 and over
Peptideum; Samuel Goldberg & Sons Foundation, Inc. in honor of the Curr family

Beneficiaries $1,000 - $4,999
Alexander & Janice Curcio, Jr.; Dermatology Initiatives, Inc.; Bernard & Barbara Green; Robert Mufson; Linda & Norman Taft

Sponsors $500-$999
Wylie Atkin; Jean Barish; G. Brian Christie; Marjory Dobbins; Edward & Michelle Essick; Alan Livingston; Henry & Liz Myers; Louis & Carol Rippe; Madelyn Rubin; Alan & Dorothy Shulman; Dr. Edward Tener

Matching Grants
Bank of America Foundation; Times Mirror Foundation; Warner Lambert Pharmaceuticals

Patrons $100-$400
Hearty & Beth Adumany; Addison Reserve Realty Limited; Terry & Sheldon Adelman; Ray & Linda Adrian; Robert Aetker, Jr.; Dr. Masayuki Amagai; Grant Anhalt, M.D.; Edward & Renee Argow; Steven J. Aronson; Edna Axe; Richard Baer; Levoa & Sarah Bardsley; Robert Barish; Ron & Cheryl Bedrosian; Ranne Beery; Darryl & Saraanna Benes; Eli Ben-Dor; Joseph Benjamin; Anthony & Colene Beringer; B'Nai Torah Congregation; Elizabeth Boyd; John & Mary Brooks; Steven & Brenda Burns; Eric & Tyson Bryne; Brest Bunger; George Burton; Lorretta & Wendell Cayton; Julian Cisneros; Carol Clopper; Allen & Ellen Channing; Wei Chen; Richard Chen; David Chugh; John & Sandra Cissell; The Cogan Family; L. Jay Cole; David & Victoria Collins; Joyce & Joe Cone; Julian Corrigan; Michael Custer; Roseanne & Ken Daukantas; Joan DeLuccia; Linda DeLuccia; Design Polymers; The Dzigajewski Family Foundation; Alvin Dobbs; Joseph Delle; Bill Etesco; Edager Properties; Edward (Stib) Essick; The Equitable Foundation; Mr. & Mrs. Estin; Kim Fahrendorf; Paul Feldstein; Sandra & Herb Feldstein; William Fenn; Collete Floyd; Frank Floyd, M.D.; Betty Foster; Edward & Lynn Franklin; Daniel Frankenstein; Garcia-Brenner & Partners; Garnier Manufacturing, Inc.; Geosystm Consultants, Inc.; Mark & Nancy Gilchrist; Marcello Goldenstein; Brette Gordon; Albert & Jane Gortz; Lois Green; Arthur Greenberg; Howard Grossman; Mark Grossman; Stuart Grossman; Michael & Janet Hamilton; Mary Lou Harvey; Takashi Hishimoto; Leo & Tricia Heinz; Kathleen Hernandez; Norman & Dorothy Hitehock; Wesley P. Hoffman; Felicia Hutzel; David & Inka Isi; Brian Smith; Jeanette & Associates, Inc.; Jane Johnson; Jewish Community Fed. of Broward County; Rick & Anne Kelder; Dr. Francisco Kerdell; Nancy Kessler; Mary & Thomas Kirstein; Mr. & Mrs. Ron Klein; Sylvia Konicov; Leslie Koonce; Ronald J. Kora; Bernard Kotlik; Carolyn Kranberg; Elliot Kresser; Fred & Rose Kresser; Bryan & Lisa Krumelf; Russ & Mary Susan Letherby; Don & Beth Leonard; Marlan M. Leber; Leilaclo Funeral Home; Ray Lombardo; Robert & Linda Levy; Stanley Love; Robert & Jill Lyman; Arthur D. Lynn Jr.; Eileen Lucey; Sherman Ma; Louis Main; Michael Main; Thomas & Lodovica Main; Joyce & Jack Mandel; James Maple; Michael & Sandy McClure; Master Gardeners Nursery & Landscaping; Michael McLaughlin; C.R. & Gloria Medeiros; Ron & Cathy Merriman; Milwaukee Jewish Federation, Inc.; Gitan W. Mirowski, M.D., M.D.; Newhouse Specialty Co., Inc.; Bruce Nor; Robert Russbbaum; Don & Holly Ohtig; Dr. Aebayeye Osi; Martin & Pamela Ots; William & Geraldine Pauls; Simon Pearlman; & Associates; Pat Peckham; Richard & Doreen Penfield; Marcia Pepper; Mildred Pepper; Melissa & Jeffrey Perry; Pinnacle Surety Services, Inc.; The Planning Center; Karen Polak; James Pollock; Shane & Dusan Pusice; Tumi & Sheila Quirk; William S. Rehrick; Mark & Cindy Richardson; Joyce Rice, M.D.; Leon Riebman; Carolyn Rich; Millie Dunn Rogers; Jennie Romero; Sandra Rose; George Rudolf; Linda Sanchez; Nina Salove; Helen Schnecker; Richard Schwartz; Stanley & Joan Schwartz; Bernice Schroeder; Curtis T. Schultz; James Sciarbba, D.M.D., Ph.D.; Keith Scott; David & Andrea Segall; Evan & Jean Segall; Paul & Patricia Sears; Robert Severson; Shaving Products Group; J.B. & Jerry Sheer; Gene Shuman; Russell Silverstein, M.D.; Raymond & Arthyk Smith; Susan H. Smith; Southern California Grading Co.; Mark & Christine St. Clare; John R. Stanley, M.D.; Steven Stevens; Robert Swerlick, M.D.; Richard Sziebenak; Technic Computer Systems Corp.; Sonia Tramel; Mark Vans; Gary & Wade Vodan; Schick, a division of Warner-Lambert; Elizabeth Weinreb; Victoria Werth, M.D.; Williamson Construction; Mary (Caye) Whitson; Reddy Wolf; Terri Esther Wofsky; Abdullah Al Maamoun Zahid; Marvin Zale; Esther Zaret; Zaret Foundation Jewish Federation

FRIENDS $50-$99
Aho-Ai, Inc.; Cynthia A. Alexander; Jose Alvarez; Gene & Miriam Arnow; Gorali Banks; Richard Basker; Polly Berggrun; Ernest Beutner, Ph.D.; Mike Bieke; Eugene Belfari; Salvatore M. Bonanno, D.D.S.; Leon Brauner; Linda Breau; Melbrim Burs; Susan Roller Burks; Jean-Claude Bystryn, M.D.; Mario & Deborah Cellura; Albert & Eva Chalkes; Michael T. Chance, Jr.; Desikan & Vadnya Chari; Judy & Paul Chechelle; Annie Chin BeDell; Daryl & Jackie Chin; Nicolina Clark; William & Robyn Collins; M. Kari Connolly; Angela Cordisco; Kevin Crumley; Robert B. Curland; Keith & Pamela Curry; Mark & Heather David; Greg & Joan Davis; Vince Dippold; Arthur & Shirley Doig; Richard Dukas; Nancy Eagle; George Noble Edwards; William & Corinne Elhai; Kurt Emming; Dr. John E. Fantasia; Dorothy Feinstein; Dr. & Mrs. Steven Feinstein; David & Vi Feldstein; Phyllis Felder; Mark Fitzerman; Robert Fitterman, M.D.; Tom & Catherine Foley; Harold & June Forrest; Dewey Fowler, Jr.; Grace Finkel Friedman; Tony & Karen French; Cheryl Garnett; Roberta Gillis; Robert & Patricia Gillman; Roseanne Herzog; Leslie Hilt; Helen Hoang; Mr. & Mrs. Thomas Hoffer; Barbara Holleb; Gloria House; Ronald & Donna Hovess; P. Michael Huest; Margaret Iannitti, M.A.; Farnocia Insurance Agency; Dr. David Jacobson; Archi Jaffe; Robert Janis; Harlow & Anne Johnson; Jane Joseph; Robert Jostes; Leslie E. Kaplan; Bob Kavabo; Phyllis Kezner; Ira Kleinsrock; Lee Kottok; Dania & Gene Krousk; Tiffina M. Krzywicki; Esther Laks; Pamela Lastie; Mr. Leon; Stephanie Lester; Stuart U. Levine, D.P.M.; Robert Levy; Dr. & Mrs. Steven Libby; Alan Livingston; Neil Korman, M.D.; Philip Lynn, Jr.; Thomas & Catherine Mannaly; Harriet McCabe; Francie & Virginia McCarthy; John Meador; Donald & Janet Meyerson; Mila Milani; Mary Miller; Roberta & Wiley Miller; Grace Minahan; Ed Monod; Donna Muniz; Cecilia Murphy; Barry & Iris Nelson; Elizabeth Owen; Sylvain Palmer, M.D., Inc.; Amit Pandya, M.D.; Denise Paton; Sandra Pazzini; Simma Pearlman; James & Lillian Pell; Tracy & Barry Pellman; Sally Per; S. Douglas Persaud; Patricia Persaud; Martin P. Persson; Jean Quezelle; Venus Rastogi; Debabrata & Anjali Ray; Millie Dunn Rogers; Barbara Ritter; Gertrude Ritter; Gloria Romanio; Noah Rosner; Charlotte Roth; Howard Roth; Mary Eliza Rusnov; Susan & Stephen Ruthven; Nick & Traci Roykawi; William L. Levy Sacks; Angelina Savaggio; Elaine Schenker; Lee Schuer; Bernice Schroeder; Erol & Janice Schubot; Judith & Robert Schwartz; Helen Segall; Gerald Sebbert; Lupe Sharp; Steve Sher; Joseph Shires; Linda Sims; Joan Shorr; Sherry Scamilton; Melvin & Dorothy Shy; Charles Smith; Raymond & Margaret Smith; Susan & Helen Smith; Gary Spier; Jack & Minnie Spier; Stan & Judy Steed; Sloan Stevens; Arlene Stratus; Katherine Sylvester; Samuel & Helen Szelboum; Paul Takiguchi, M.D.; Gene Talbot; Victoria Thompson; Melvin & Ann Voegeli; Kimberly A. Walker; Westchester Gym. & Obstric tin; Calfeld & Wheeler, Inc.; Rose D. White; Anita Weiss; Miriam Weiss; Richard Wies; Sandra Williams; Beverly Wilson; Elle Wittenberg; Jody Wittenberg; Wallace Wolman; Carolyn Wong; David Zarei
Progress continues to build in United Kingdom

By Siri Lowe
PV Network
London England

It has been almost a year since I last wrote anything for the Quarterly, so this is to let people know what we’ve been doing here. We carry on getting a regular stream of new enquiries from people with pemphigus—about 70 since the last article. Some people find us through information databases and past mentions in the media, but more now come through dermatology nurses and the Foundation website.

Although few people seem to have access to the Internet personally, they say that a friend or relative looked up the website and found out about us. It’s really encouraging to see what a great impact the website is having, and I’m sure there are lots of other people who look up the site, find our what they want and don’t need to get in contact with us. I still feel our most important work is simply being there for people, particularly when they’ve just been diagnosed. But we’re also very involved in development and publicity work—particularly trying to reach dermatology doctors and nurses.

1998 was a really busy year for that. In the summer Zoe and I had an information stall for one day of the British Association of Dermatologists’ Annual Conference, and that gave us a chance to talk to quite a few doctors and nurses and let them know about us and about The NPF.

We were also able to meet Dr. Wojnarowska, one of the main blistering disease specialists in this country. The stall was hard work and lots of fun and hopefully started the process of getting us better known.

The Skin Care Campaign, one of the umbrella groups we work with, has recently published a directory on skin diseases and patient support groups which gave us two pages to explain what pemphigus is and what it’s like to live with, as well as giving information on the PV Network, the National Pemphigus Foundation and the website.

The directory has been circulated mainly to hospitals and some other health professionals and we’re hoping that it will be a resource that’s well used by hospital doctors.

In December we went to the Houses of Parliament where I gave a presentation on pemphigus vulgaris to the All Party Parliamentary Group On Skin, which is a special interest advisory group of MPs (Members of Parliament) health professionals and patient groups. The first speaker was this year’s head of the British Association of Dermatology (BAD) and he has since organised for us a mention in their Spring newsletter.

We were very pleased that Dr. Wojnarowska kindly wrote a brief piece with me for this. Our other line of “getting ourselves known” has been via dermatology nurses.

Having the information stall at the B.A.D. Conference meant we were able to meet the chair, editor and members of the nurse’s committee and develop good working links with them.

Later in the year I’m getting together with last year’s chairwoman to write a piece for their magazine and I was asked to contribute “a patient’s view” to a chapter she’s been writing for a medical textbook. In the UK it’s often specialist nurses who pass on information to patients, so the more work we can do together the better.

Looking back on what I wrote last year, it’s good to realise that we have a much stronger presence now and there are lots of ways people can find out about pemphigus and the PV Network.

---

The National Pemphigus Foundation is proud to present:

The Anhalt Tape

A video lecture by Dr. Grant Anhalt of Johns Hopkins on current views into the basic biology of pemphigus

Dr. Anhalt is Chairman of the Dermatology Department at Johns Hopkins University Medical Center in Baltimore, Maryland. He is NPF Vice President of Scientific Affairs and Chairman of the Medical Advisory Board. He is one of the world’s leading researchers into pemphigus.

This illustrated material is not available in a similar format anywhere in the world. The price reflects production costs and a small amount to generate additional educational materials.

PROFESSIONALLY PRODUCED, AVAILABLE IN VHS FORMAT ONLY, APPROX. 60 MINUTES, SUGGESTED DONATION OF ONLY $150.00*

PRINT CLEARLY. Mail to: The NPF, 628 San Pablo Ave. Suite 203, Albany, CA 94706. Please enclose check, money order, Visa or Master Card. No.__________________________ Exp date: MO:____ YR:____

Number of copies ordered:_____________________

Name:_____________________________________
City:______________________________________ State/Country:_________________________
Postal Code:_______________________________

*U.S. FUNDS ONLY PLEASE, PRICE INCLUDES POSTAGE AND HANDLING. IF THIS AMOUNT IS A HARDSHIP, PLEASE CONTACT THE FOUNDATION.

Continued from page seven

Statistically more likely to suffer depression, the odds are stacked against the family caregiver. Studies show that other people are more likely to see the early signs of depression than the person who is suffering with the condition.

Caregivers should see their own doctors, as well as connecting with friends and family outside the home. These are the people who will be able to see changes in personality and assist in getting help before things get out of hand.

Finally, what caregivers and pemphigus patients must remember above all is that it is not their fault. Little is known about what triggers pemphigus, and some of the treatments feel as though they are worse than the disease itself. None of this can be blamed on anyone, nor does it help to assume responsibility for something which is obviously beyond control. Talk about it, get help, use the help and then talk about it again.

Each patient needs to map out his or her individual recovery plan which is multifaceted and requires teamwork. With the help of doctors, family and friends, patients should define what issues are important.

Since pemphigus affects people in such a wide variety of ways, and changes over time, it's not possible to make suggestions for details here. Each family will know what is most important to them, and can then make sure that all the care providers have that information. What is being created is a network which has the patient as the focus. It's critical to remember that the goal is to make things easier for everyone involved.

The patient needs to set the pace, with the knowledge that there will be adjustments as the disease unfolds. The rewards to the caregiver can include anticipation of the time when their attention is no longer as necessary. The darker days are temporary, and eventually, with patience and determination, the joys of life return with a new-found appreciation, and the bond between patient and caregiver can only grow stronger and closer.

CPA-SDR lobbies Congress

Continued from page one

Age congressional representatives to sign a letter advocating the substantial increase in NIH funding.

At the dinner meeting, Segall met Dr. John Stanley, who has been a longtime pemphigus physician and researcher, and supporter of the Foundation.

The following day was a breakfast meeting at which Dr. Katz spoke again, and an award was presented to Senator Arlen Specter (R-Pennsylvania), for his relentless support of the NIH and work to keep the NIH budget at its highest.

Representatives then split up into groups and visited several Congressional Senators and Representatives relaying to them the importance of supporting the 15% increase in funding.

If we don't tell you, who will?

To subscribe please detach the form below and return to:
The National Pemphigus Foundation
828 San Pablo Avenue, Suite 203, CA 94706. Print clearly.

☐ I would like to receive the quarterly newsletter. I enclose my suggested annual donation of $50.00* ($65.00 outside the United States) to help offset the costs of the NPF website, the online support group and the quarterly newsletter, etc. Please make contributions in U.S. funds

☐ I would like to donate an additional $_______ to further the work of the NPF.

☐ I would like to receive the newsletter, but I am under a financial hardship. I enclose a donation of $_______ to help cover the costs.

Visa or Master Card: ____________________________
Expiration date: MO: ___ YR: ___

Name: _________________________________________
Address: _______________________________________
City: __________________ State/Country: ___________ Postal code: ___________
Telephone: (_____ ) ______ Date: __________
If you need to talk to someone about pemphigus, contact one of our volunteers.

Arlene Strauss (Group leader)
514 Inverary Lane
Deerfield, IL 60015
847-940-1440
ChicagoPV@aol.com

Peg Schroder (BP)
3034 Grand Concourse
Bronx, NY 10458
718-584-3392

Miriam Weiss
Brooklyn, NY
718-332-2681

Lousiana
Lillie Clemons
P. O. Box 1196
Coushatta, LA 71052

Venus Raslegar
P. O. Box 3653
Santa Monica, CA 90408-3653
venus_raslegar@es_xerox.com

Massachusetts
Loretta Mineo
4 Lowe Dr.
Magnolia, MA 01930

Maryland
Elaine Guice
2909 Salsbury Ave.
Baltimore, MD 21219
410-477-9445

New Jersey
Marian Leber (BP)
New Jersey
732-657-9694

Virginia
Nicholas Moskowitz
2108 Providence Place,
Richmond, VA 23226-1856
804-726-0853
sendervoich@firstsaga.com

Wisconsin
Peggy Proeber
5721 Hilcrest Lane
West Bend, WI 53095
414-629-9101

Wyoming
Brenda Schulz
10630 Porteous Phillips Rd.
Cheyenne, WY 8209

Australia
Julian Chan
08-9316-1787
Fax: 08-9364-3623
18 Stanbury Way
Booragoon WA 6154
juchan@cc.com.au

Canada
Dan Goodwill (Group Leader)
105 Hillhurst Blvd.
Toronto, Ontario, Canada, M5N 1N7
416-488-0453

England
The PV Network
Flat C 26 St. Germans Rd.
London SE 23 1RJ, England
(please enclose a self-addressed, stamped envelope)

Israel
Victor Leikeman
052-235412 (Cellular)
victor@act.com.co.il

New Zealand
William Eaton
176 Ngaire Ave.
Auckland 1003
New Zealand
william@pnet.co.nz

Dorothy Muniz
211 Jacob Court
St. Jacob, Il 62281.com
Salt: are you already getting enough?

By Hannah Lisa Reade

Since Prednisone can cause water retention and puffiness, we need to keep our sodium chloride levels down, but not totally eliminated. Most people have been conditioned to a salty taste by nutrient-poor refined carbohydrates commonly known as snack foods. Sodium occurs naturally in foods and it is not necessary to add sodium chloride to foods to be healthy; quite the contrary.

What it does: Sodium and potassium need to be in balance so that nutrient and waste exchange can take place across cell membranes. Sodium is also necessary for the production of hydrochloric acid, the digestive enzyme secreted by the stomach to digest protein. It is required for the proper functioning of our nerves and the contraction of our muscles. It is also required for fluid balance, electrolyte balance and pH balance. Too little sodium can cause impaired carbohydrate digestion, and possibly neuralgia.

Dietary Allowance: Normal blood levels of sodium are 137-144. The estimated RDA for healthy adults is 500 mg. Some experts say you need 2000 mgs per day if under stress. Over 14 grams is toxic. One teaspoon is 2000 mgs, 1/8 teaspoon is 250 mgs.

Types of Sodium: Naturally occurring sodium in foods is desirable; table salt is not. Refined table salt is stripped of all its minerals except sodium and chloride. It is heated to high temperatures, bleached, treated with anticaking agents such as the toxic alumino-silicate. This prevents dissolution in the fluids in our system. The aluminum leaves a bitter taste so the manufacturers add dextrose, a refined sugar, which disrupts the body's equilibrium.

Natural Sources: shellfish, carrots, beets, artichokes, kelp, and natural cheeses. Unrefined sea salt, or a rock salt called Real Salt. Both these salts contain naturally occurring iodine. Potassium, magnesium, and calcium counteract the effects of excess sodium.

Dangers of too much sodium: Too much sodium can cause a depletion of potassium, and often high blood pressure (hypertension), which can lead to stroke and heart failure. Excess sodium causes calcium to be lost through the urine, and can contribute to osteoporosis. The resulting fluid retention can also stress the heart and circulatory system. Bloating (edema) often causes irritability and depression. Headaches and migraines can be caused by eating substances with sodium such as MSG (which by the way, has excitotoxins which can damage and kill nerve cells), sodium sulfites, nitrates (usually found in luncheon meats), and nitrates. Salt has long been indicated as a cancer threat to the stomach, especially in collusion with other carcinogens, such as residues and smoke from barbecuing and grilling meat. Salt is an irritant to the stomach that can induce gastritis, increases precancerous cell replication and boosts the potency of chemical carcinogens causing stomach cancer, and ulcers. The American Heart Association reports that blacks have a greater sensitivity to salt and a higher rate of hypertension.

Foods with high sodium: luncheon meats, hot dogs, cured meats (such as ham, bacon, corned beef), ketchup, chili sauce, soy sauce, mustard, baking powder and baking soda. Ninety percent of the sodium Americans consume comes from processed foods. Just read the labels you’ll be shocked at the percentage of sodium. Sodium added because there is no flavor in the food to begin with and salt makes it edible.

Factors affecting need for sodium: Older people, overweight people, and people who have kidney damage are more sensitive to salt intake. Those that exercise a lot, live in high elevations, have vomiting or diarrhea and vegetarians (because of excess potassium) need more sodium. Check with your doctor. Exhauation makes you want more salt to stimulate your metabolism, but it won’t help.

Symptoms of low sodium levels: People under prolonged stress can have low sodium levels because of weakened adrenal glands. Symptoms are allergies, chronic fatigue, flatulence, low blood pressure, cold hands and feet. If you crave salt it can be sign your adrenal glands are depleted due to stress.

Snacks without much sodium: celery spread with unsalted nut butter, sliced jicama (marinate in lemon juice, later add chili powder, red pepper), veggies dipped in a yogurt and dill weed sauce, whole grain pretzels without salt, air popped popcorn with herbs (or cayenne, or chili, and canola oil) unsalted baked Tostidos with low-salt salsa (tomatoes, scallions, chilies or jalapeno, red wine vinegar) tortilla chips dipped in warm refried beans, unsalted nuts or unsalted dry roasted nuts, low sodium bottled water (Evian) or seltzer, low sodium V8 or tomato juice with hot sauce.

Cooking: If you add salt after cooking, it will taste stronger and you can use less. Cutting down on sugar and alcohol can minimize salt cravings. Use lemon, mustard greens, or radishes for flavor. High sodium vegetables such as celery, carrots, parsley, chard, spinach, and kale can impart a salty flavor to cooked foods. Use fresh (under 6 months old) ground herbs and spices to jazz up foods. Fresh herbs can be frozen. Mrs. Dash (available in the spice section of your grocery) has a selection of salt-free seasonings, some are without garlic and onions for those who are sensitive. Herbed olive oil, or herbed vinegar (Spectrum Naturals have no added sulfites). Taste before you salt your food.
Make room reservations by July 7

Experts and expanded programs highlight second NPF conference

The skyscrapers and bright lights of New York City will be the backdrop of the National Pemphigus Foundation’s second annual conference, July 31 and August 1, 1999.

This year’s conference will be held on the campus of New York University (NYU) Medical Center at 550 First Avenue between 30th and 32nd Streets in the Greenwich Village borough.

Each ticket for the two day affair is $75 and includes entrance to all educational presentations and several meals. The main banquet is Saturday, which will be preceded by hors d’oeuvres and a no-host cocktail party.

The planning for Saturday’s program is in its final stages. Already scheduled are two speakers from the Foundation’s Medical Advisory Board, Dr. Joyce Rico and Dr. Victoria Werth, who will speak on their specialties. Dr. Joyce Rico, from NYU, will speak on BP. Her question and answer session was one of the more popular features of last year’s conference. Dr. Victoria Werth, from the University of Pennsylvania, will address the effects of Prednisone.

Dr. Ben Bronstein, CEO of Peptimmune, has also committed to discuss progress on their research into a vaccine against pemphigus.

Sunday’s speakers include a psychologist and a government health official who will speak on health care.

Those planning to attend must return the enclosed reservation form with payment before June 15.

Guests are to make contact the hotel reservations desk directly. The New York Helmsley Hotel is taking reservations for the conference. The cut off date for reservations is July 7, 1999. Be sure to mention the NPF to get the discounted room rates. Contact numbers are in the box on this page.

Room rates are $150 single/double occupancy or $180 triple occupancy. Reservations after this date will be at the prevailing rate on a space available basis only. Check-in time is 4:00 PM, checkout is noon.

Those wishing to share a room should contact Janet Segall at the new Foundation headquarters or notify Joan DeLucie.

For those interested in extracurricular activities, the Foundation is organizing a trip to the Broadway musical comedy, Forbidden Broadway, Friday July 30. Tickets, are $35 each. Mark the registration form if you are interested.

Last year’s event could not have been more successful, and this year promises to be even more educational, invigorating and fun. Learn from the experts and meet the rest of our family.

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

We have moved!!!

We’re online: www.pemphigus.org