The third annual NPF conference
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Letter campaign
We need your help to establish an Office of Immunology at NIH.
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NPF to sponsor meeting at NIH
In Association with the NIH (National Institutes of Health) and American Autoimmune Related Disease Association (AARDA), the National Pemphigus Foundation will present a two day conference at NIH in Bethesda, Maryland April 20-21, 2001. The subject is "Pemphigus as a model of organ-specific humoral autoimmune diseases." Lead by NPF Medical Advisory Board members Jean-Claude Bystryn, Grant Anhalt, Luis Diaz and John Stanley, this conference will present research and opinions on pemphigus. With speakers from around the world, the role of pemphigus and autoimmunity will be discussed thoroughly.

Ten advisors speak at AAD
Ten of eleven physicians on the NPF Medical Advisory Board spoke and/or taught courses at the 58th annual meeting of the American Academy of Dermatology held in San Francisco, March 10-15, 2000.

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Drs. Grant Anhalt, Masayuki Amagai, (who flew in from Japan), Jean-Claude Bystryn, Luis Diaz, Robert Jordon, Francisco Kerdel, Deidre Murrell (who flew in from Australia), Joyce Rico, James Scibba and Victoria Werth all gave presentations. No is working in Israel.

The presentations covered a wide variety of subjects ranging from "Cutaneous Oncology" by Dr. Bystryn to "the Dermatologic health of women" by Dr. Rico to Immunology lead by Dr. Anhalt and including Dr. Diaz.

In addition to being members of the faculty of the AAD, Dr. Jordon chairs the Manpower Committee and serves on the Ethics Committee and the Health Policy, Practice and Research Committee. Dr. Diaz is on
The National Pemphigus Foundation

A common hope, an uncommon bond*

The National Pemphigus Foundation is a 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 people living with pemphigus or pemphigoid, their friends and families; to provide referrals to specialists; and to support research into advanced treatments and cures. Founded in 1994.

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The material presented in our journal is not intended as medical advice. Readers are urged to consult with their physicians before making any changes in their health regimes. The opinions of contributors are not necessarily those of the NPF.

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We hope to offer a $10,000 research grant this year

We would like you to help us to raise at least $10,000 for research. We would like to see everyone get involved in some way. Almost all the money we raise this year will go into a research fund, and we hope to support an investigator's project by the end of the year. We have several interesting projects in mind.

There are many ways you can help us. You can have a bake sale, or a garage sale (it is spring cleaning time). An amateur contest can be put on with the help of your local church, synagogue or school. We are looking into the possibility of raffles. To date, however, we can only do those in New York and California, because those are the two states where we have nonprofit status. If anyone in another state would like to do a raffle, please call your Secretary of State's office and find out the procedure. If you get the information, we can do the paperwork. The research that is being done on pemphigus (and on pemphigoid) is very good but not enough. The NIH believes that pemphigus research is getting more money than many other rare and orphan diseases. But, as we have mentioned, pemphigus research is very important not only for pemphigus sufferers, but for finding solutions to other autoimmune diseases as well. It is a one-organ disease, and because it is on the skin surface, easy to see.

Now that we are able to meet our operating expenses, we can move forward. Our newsletter and website have been touted as being the best lay information available on pemphigus and pemphigoid anywhere. The continued support of many committed doctors to our cause has helped put the Foundation where it is today; doctors who have committed themselves and their time to making sure we get the best care we can get. Now let us introduce ourselves to the public. Let's let people know about our disease. Having a disease like pemphigus is nothing to be ashamed of. You cannot be fired from your job for having pemphigus. I wish they had given it a different name. I must admit that pemphigus is not a very media friendly name, but once you get used to saying it, it grows on you.

Diseases like pemphigus - autoimmune diseases - affect far too many people. As I've mentioned before, autoimmune diseases are the third largest group of diseases, next to heart disease and cancer. We spend billions of dollars a year treating these diseases. Finding a cure or better treatment for pemphigus could be the first step in this puzzle. Since the Foundation is supporting the bill to establish an Office of Autoimmune Diseases, we are hoping that this office will direct more funds towards finding better treatment or a cure for pemphigus. But, we believe we now each must do our part in helping ourselves get better. If we can raise the money we need to provide one small research grant, we are taking a big step in the right direction.

I have had 13 new inquiries just this month and it is only the 9th. We are getting almost one call or email or letter a day asking for help and information. I'm hearing from more young adults, teenagers and children than I want to. Many of us live very successfully with pemphigus/pemphigoid, but we cannot forget those who do not. Join the Foundation in our efforts to help our scientists find the answers.

On another note: recently, I have sent out to everyone a letter asking you about your interest in attending our annual meeting. (See facing page). This year, the meeting is being held in San Francisco. If you are planning to attend, please do not forget to fill out the form and send it back to the Foundation office. It is important for our plans to know, tentatively, how many people are planning to come.

Janet Segall
Executive Director
THE NATIONAL PEMPHIGUS FOUNDATION PRESENTS

THE THIRD ANNUAL DOCTOR/PATIENT CONFERENCE

SUMMIT IN THE CITY

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SATURDAY, SEPTEMBER 23, 2000
9:00 AM TO 5:00 PM

AT THE HOLIDAY INN AT THE WHARF
SAN FRANCISCO, CALIFORNIA

Join us in one of the world's favorite cities, San Francisco! This year's collection of doctors and patients offers every bit of the same kind of expertise and access enjoyed at the first two conferences. Dr. Grant Anhalt will speak as will Dr. Sergio Grando from the University of California at Davis and Dr. Kari Connelly from the University of California at San Francisco. Additional speakers will be announced.

The conference includes breakfast, a dinner banquet, a full day of the latest news and information about pemphigus and pemphigoid and, of course, the highly popular Question and Answer session. Optional entertainment is also being planned. So come to "the City" see some sights, pick up some nuggets from the experts, meet old friends and make new ones. Don't miss this golden opportunity.

THE FOCUS IS ON TREATMENT THIS TIME, DON'T MISS YOUR CHANCE TO ASK YOUR QUESTIONS FACE TO FACE!

Copy or cut out this form, then check all that apply and return to the NPF office as soon as possible. Thank you.

___I would be interested in sharing a room, if possible.
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___I would like to take a cruise of the Bay during the day.
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Diagnostic patterns and delays in pemphigus vulgaris: experience from 99 patients

By David A. Sirois, D.M.D., Ph.D.
Mahnaz Fatahzadeh, D.M.D.
Rinat Roth, D.D.S.
Dominik Etl, D.M.D., M.D.

Introduction: Pemphigus vulgaris is a chronic autoimmune disease affecting the mucosa and skin resulting in epithelial acantholysis, bullae formation, and chronic ulceration (1). Skin lesions of pemphigus vulgaris present clinically with typical bullae formation and ulceration. However, oral mucosal manifestations are less characteristic, typically appearing as multiple, chronic mucosal erosions or superficial ulcerations of various size and rarely presenting with intact bullae (2). Although pemphigus vulgaris is widely considered a skin disease, several cases and case series have described it frequently as the initial, and occasionally as the exclusive, site of involvement. (2, 3). Thus, the unfamiliar features of oral pemphigus vulgaris could result in longer diagnostic and treatment delays than cutaneous pemphigus which could adversely affect treatment response and prognosis. (4, 5). This study explored the natural history and diagnostic pattern of pemphigus vulgaris among 99 patients with specific interest in the differences between oral and cutaneous pemphigus.

Patients and methods: A questionnaire was mailed to the membership of the New York Chapter of the National Pemphigus Foundation and also distributed to attendees at the national conference of the Foundation held in 1998. A total of 99 questionnaires were completed: of the 64 mailed questionnaires, 52 members responded (81%) and an additional 47 non-duplicated individuals attending the national meeting completed the questionnaire. To minimize selection bias the questionnaire was made available to patients without regard to the site of their lesions or the type of treating clinician. The questionnaire collected the following data: specific diagnosis, present age; age at diagnosis; sex; prevalence of oral, cutaneous and combined mucocutaneous lesions; site of initial lesions (oral mucosa, skin, other) and site of most problematic lesions; time between onset of skin and oral lesions; the number of clinicians consulted and biopsies performed before a correct diagnosis was established; and present medications.

Table 1. Demographic and Lesion Chronology Findings (n=99)

<table>
<thead>
<tr>
<th>Sex</th>
<th>n (%)</th>
<th>Present Age</th>
<th>Age at Diagnosis</th>
<th>Duration of Illness (years)</th>
<th>Interval between skin &amp; mucosal lesions (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>22 (29%)</td>
<td>52.3±11.2</td>
<td>48 ±10.8</td>
<td>5 ±4.1</td>
<td>8.8 ±8.1</td>
</tr>
<tr>
<td>Female</td>
<td>52 (71%)</td>
<td>56.1±11</td>
<td>50 ±11.2</td>
<td>6.6 ±6.1</td>
<td>7.6 ±7.9</td>
</tr>
</tbody>
</table>

* applies only to those patients who had both oral and skin lesions.

Results: Table 1 summarizes the demographic characteristics and lesion chronology of the group. Table 2 summarizes the distribution of lesions and diagnostic patterns. 80% of patients experienced oral lesions as the first sign of pemphigus vulgaris. Throughout the history of their illness, 69% experienced both oral and cutaneous lesions, 24% experienced only oral lesions, and 7% experienced only cutaneous lesions. 67% of patients stated that oral lesions were more bothersome than skin lesions, mostly due to pain while eating. Whereas 100% of patients with PV on the skin were correctly diagnosed within 6 months requiring about 2 physician contacts, 29% of patients with oral PV experienced diagnostic delays greater than 6 months requiring more than 4 clinician contacts. Patients with cutaneous lesions seek diagnosis and treatment nearly exclusively from physicians, whereas those with oral PV lesions seek care from both physicians and dentists equally.

Table 2. Distribution of lesions and diagnostic patterns

<table>
<thead>
<tr>
<th></th>
<th>Oral Lesion</th>
<th>Skin Lesion</th>
<th>Skin and Mucosal Lesion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site of first lesion</td>
<td>79 (79.8%)</td>
<td>20 (20.2%)</td>
<td>-</td>
</tr>
<tr>
<td>EXCLUSIVE site of lesions</td>
<td>24 (23.7%)</td>
<td>7 (6.9%)</td>
<td>69 (69.4%)</td>
</tr>
<tr>
<td>Diagnosing clinician</td>
<td>Physician 53%</td>
<td>Dentist 47%</td>
<td>Physician 100%</td>
</tr>
<tr>
<td>Diagnostic delay</td>
<td>71% ≤6 months</td>
<td>18% 7-12 months</td>
<td>11% &gt; 12 months</td>
</tr>
<tr>
<td># clinicians to achieve diagnosis</td>
<td>4.28 ±3.5</td>
<td>2.08 ±1.31</td>
<td>-</td>
</tr>
</tbody>
</table>

Conclusions: Eighty percent of patients with pemphigus vulgaris experience oral lesions first, and the disease remains limited to mucosal surfaces in one out of four patients. Diagnostic delays greater than six months are common in oral pemphigus vulgaris, a finding of particular importance since early diagnosis and intervention may prevent disease spreading. Oral pemphigus vulgaris is less commonly recognized than cutaneous pemphigus vulgaris, requiring more clinician consultations associated with increased health care utilization and costs. While patients with skin lesions typically seek help from physicians, those with oral lesions seek help equally from physicians and dentists. When a patient presents with multiple, chronic oral ulcerations, pemphigus vulgaris should be included in the differential diagnosis.

References:
A review of two articles found in medical literature

By Edward Tenner M.D.

I want to highlight two articles from 1999 that deal with the etiology of pemphigus and the diagnosis and treatment of pemphigus and pemphigoid. They are very detailed and would be good reviews for patients who want to learn about the scientific basis of their disease, or for doctors who want the latest information on these rare disorders.

"Pemphigus-Diseases of Antidesmosomal Autoimmunity" by Drs. Mark C. Udey and John R. Stanley appeared in the August 11, 1999 issue of J-A-M-A: 282:572-576. It is a grand rounds discussion for the National Institutes of Health where a patient with pemphigus is presented. The following discussion of the pathophysiology (etiology) of pemphigus discusses in detail how autoantibodies against desmoglein (a protein that helps to hold skin cells together) cause pemphigus. It details how the immune system is stimulated and why there is a genetic predisposition to pemphigus in certain populations. Nice illustrations show the makeup of desmosomes (the organelle that hold cells together) and explain the desmoglein compensation hypothesis.

This hypothesis is the basis for autoantibodies against desmoglein 3 and desmoglein 1 causing different clinical presentations i.e. Why blisters in pemphigus foliaceus are more superficial than in pemphigus vulgaris and why oral involvement is found in pemphigus vulgaris but rarely in pemphigus foliaceus. It summarizes what Dr. Grant J. Anhalt explained in his article “Why blisters occur at different sites” in the Spring 2000 NPF newsletter.

The other article is by Drs. Hossein C. Noursari and Grant J. Anhalt in the August 21, 1999 issue of The Lancet 354:667-672. Titled "Pemphigus and bullous pemphigoid" it is a seminar on the diagnosis and treatment of these diseases. It is a primer on how to make the diagnosis of these diseases and how they are typically treated. I will highlight one section that lists the four diagnostic criteria for pemphigus vulgaris. They are: (1) typical clinical findings, (2) evidence on microscopic examination of a biopsy specimen of intraepithelial acantholysis (splitting of the skin, a blister), (3) evidence of IgG autoantibodies bound to the cell surface of skin cells from a patient’s biopsy by direct immunofluorescence, and (4) evidence of circulating antiglobulin (against the skin cells) autoantibodies by indirect immunofluorescence or autoantibodies specific against desmoglein 3 by ELISA testing. Serum from a patient’s blood is used to do these tests.

Fulfilling these criteria will prevent misdiagnosis and allow proper treatment to be started. Together these articles give a full picture of what is happening with pemphigus and pemphigoid.

The Anhalt Tape

A video lecture by Dr. Grant Anhalt of Johns Hopkins University on the current views surrounding 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.

Suggested donation of only $150.00*

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Country: __________________________ Postal code: ______________ Date: __________

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...new Board member is NY supreme court Justice

Continued from page one
and falls, Board of Education, labor law, etc. cases.

Born in Brooklyn, the only daughter and
youngest of three children of Avis Griffin Tay-
lor and Walter Earl Taylor, Justice Taylor has
been a resident of southeast Queens since the
age of four.

Educated in New York City public
schools, she majored in both English and Po-
litical Science at the College of William & Mary
in Williamsburg, Virginia, where she received
her bachelor’s degree in 1975. She received her
Juris Doctor degree from the State University
of New York at Buffalo School of Law in 1978,
and was admitted to the New York State Bar in
March of 1979. That same year, she was also ad-
mitted to practice before the U.S. District
courts of the Eastern and Southern Districts, and
in 1983 was admitted to practice before the U.S.
Supreme Court.

Prior to her ascension to the bench, Justic-
Taylor worked as an attorney and associate
attorney with the New York City Transit Author-
ity, and was a Secretary of the Staten Island Rapid
Transit Operating Authority from 1978 to 1986,
specializing in labor, employment and contracts
law. She then spent a year working as assistant
general counsel with District Council 37,
AFSCME, AFL-CIO. Later in 1987, she entered
private practice and specialized in labor, civil
rights, family, estates, conservatorship/guard-
ianship and entertainment law, with her most
notable client being her cousin, Max Roach, a
world-renowned jazz percussionist.

She was also appointed as the first female
Referee in Conservatorship in Queens County
and served as Adjunct Associate Professor of Law
at St. John’s University, College of Business Ad-
ministration from 1993 to 1994.

Since 1991, she has been a member of the Advo-
cacy Board of the School of Paralegal Studies at
Long Island University. Justice Taylor serves as
an advocate for many community and civic organiza-
tions, including being a Board member of the Judicial
Friends Foundation for the Improvement of Justice,
Inc.; Queens County Women’s Bar Association
and the Jamaica Service Program for Older
Adults, Inc.; Legal Redress Chair and attorney
for the Jamaica Branch of the National Asso-
ciation for the Advancement of Colored People;
and President of the Macomb B. Allen Black Bar
Association.

Justice Taylor is also a member of the Ju-
dicial Council of the National Bar Association,
the Association of Justices of the Supreme
Court of the State of New York, a Deaconess
at the Concord Baptist Church of Christ and is
a member of the Delta Sigma Theta, Inc.
sorority, the Links, Inc., Top Ladies of Distinc-
tion, Shirley Chisholm Cultural Institute for
Children, the Women’s League of Science and Medi-
cine and, now, the National Pemphigus Foun-
dation.

Justice Taylor was diagnosed as having
pemphigus vulgaris on June 15, 1999 after
symptoms presented for the previous two
months.

AARDA monitors progress of HR2573

By Virginia Lald
President/Executive Director, AARDA

This is an update on the bills in the House
and in the Senate that would create an Office of
Autoimmune Diseases. (See letter campaign on
page six.) House Bill HJR 2573 currently has 29
sponsors. Senate Bill S1897 has been intro-
duced, but has no cosponsors, as American Au-
toimmune Related Disease Association,
(AARDA) has primarily worked on the house
bill. AARDA has been proactive to include lan-
guage regarding autoimmune diseases in the
Children’s Health Act. A report requested by
The National Coalition of Autoimmune Pa-

tient Groups (NCAPG) and by Congress,
which reports how much money has been spent
on research for autoimmune disease, has been
received from the National Institutes of Health.
The report, produced for congress, shows a to-
tal figure for 1999 of $393,000,000, which
includes the 30,000,000-dollar increase obtained
last year. The report shows the total spent on
research for all autoimmune disease (not dis-
ease-specific).

Let’s go to Israel!

Dr. Sarah Brenner, a Medical Advisory Board member and
noted pemphigus researcher from Israel, and Janet Segall are ex-
ploring the possibility of taking a group of NPF members and
guests on a trip to Israel to meet Dr. Brenner and pemphigus
patients there.

The trip is tentively scheduled for September 2001. The
more people interested, the less expensive it would cost per
person. If you are interested in discussing this further, contact Janet
at the NPF office, see page two for contact information.
My name is Guy Norsworthy. In August of 1997, while working in my garden in the Central Florida heat, I got a bad sunburn. Well, I grew up in Florida and I’ve had sunburns before. You deal with it for a couple of days. Your skin peels and it goes away.

After a couple of days, this sunburn was not going away. The itching was getting worse and now I was getting blisters on my back, my chest and even on my face. I went to Eckerd Drug Store, bought a tube of itch cream and used it for a couple of weeks. It seemed to help with the itching but the redness and the blisters kept coming. I used peroxide. I popped blisters and the problem got worse.

My niece was visiting from Arizona, and at her insistence, I finally agreed to go to a doctor. (See, I’m a country boy and we don’t go to doctors. I wasn’t sick. I was sunburned.) Even convinced myself I was allergic to the itch cream. I went to a GP in my area who took one look and said, “I don’t know what you’ve got but that ain’t no sunburn.” She referred me to a dermatologist and I got another appointment in two weeks.

Ok, we are going on four weeks now and I looked like death warmed over. I was miserable. I had lesions all over, even on my feet. My back was so dry that I could scratch and break the skin. Almost every night when I took off my shirt there would be bloodstains. In the AM, I would find bloodstains on my sheets and pillow case. Working was difficult and getting worse. I was driving cabs, and passengers would look at me and refuse to get in. More than one person asked me if I was HIV positive.

Finally, I go to see the dermatologist and he was stunned. We did blood tests, biopsies, you name it, and everything was negative. About a week and a half later, the doctor finally called me to his office and told me I had pemphigus foliaceus. I couldn’t spell it, much less pronounce it. I’ll never forget (how I felt) while he was telling me how extremely rare it was and how there was no cure. I was going to die. I have never felt so completely alone in my life.

The doctor put me on Prednisone and two types of topical creams. He, also knowing that I had no insurance, told me that if needed he would treat me free of charge. All I would have to do is pay for my prescriptions. If it wasn’t for that, I probably would be dead, for I had no one to turn to. I had a few good friends who knew I was being treated for a skin disorder but I never told anyone about the serious stuff. I began drinking heavily (not knowing that alcohol and Prednisone don’t mix). Putting the two together is like feeding your pit bull morphine. I have always been manic-depressive. I also work in an extremely stressful environment. Being a bachelor, who had just recently ended a bad relationship, there was no one to share this load I was carrying. The PF went into remission. I weaned off the Prednisone but in six to eight weeks it (the disease) was back. For about six months I was back on Prednisone. Friends would avoid me. Family was weary of me and work was terrible. I have worked for the same company (a small family-run company) for over 10 years. My word was no longer good enough that this was not contagious. I needed to have a note from my doctor. That really hurt my feelings and I quit working for them. Even though months later I went back to working for them, that still bothered me.

I went off the Prednisone and seemed to be free and clear. I was convinced I had beaten the odds. Then in December of 99, I noticed a blister on my shoulder. I put some left over cream on it and went to bed. By the time I woke up the next morning, my back was covered. I walked into the doctor’s office without an appointment and as soon as he heard I was there, he rushed me into his office. I left there on 60 mg. of Prednisone and feeling totally defeated. I was alone and scared and the walls were closing in.

The next day, while having lunch with a young friend who had been going through a serious bout with depression, she said something that changed my life. She knew very little of what I was going through, and I didn’t bring it up because of my concern for her. She was trying to let me know that she had decided her life was worthwhile, and that one of the things that changed her mind was watching a TV program on children with cancer, and how these kids, no matter what, never gave up hope and never quit trying to live. She said “Sometimes I feel so selfish when I look at the pain in other’s eyes. They have no hope of a pain free tomorrow but yet they will not quit. They will not feel sorry for themselves. They do not want pity. All they want is love and prayer.” And “As long as I can remember the look of hope in their eyes, I will not give up again.”

She had no idea that I went to the restroom and cried, not just because I was happy that she would be ok, but I realized for the first time: I had a choice. I could sit around feeling sorry for myself, or, like her and those kids who she had seen, I could fight. I went to the library and looked up what little I could find on pemphigus. I wrote to every organization I could find from the AMA to the Center for Rare Diseases. They sent me a suggestion to call or write The National Pemphigus Foundation. You don’t know what a relief it was to find there was a NPF to write to.

Meanwhile, I am taking 60 mg of Prednisone and still working 12-hour shifts. 6 days a week. Did I mention I take care of 2 elderly parents too? I got my first packet and letter from the NPF, and was for the first time aware: I was not alone. The mood swings have been getting worse and the depression is sometimes hard to deal with. I have experienced road rage, temper flare-ups, and just plain sulkiness.

One night while looking through the NPF Quarterly, I ran across the volunteer page (Heart2Heart). I ended up calling Ann in Enterprise, Alabama and we talked for nearly an hour. All this time, I had felt no other human could possibly know how I felt. Here was someone who not only knew what my frustrations were, but also dealt with the same one. She gave me some great advice and I appreciate her very much. I felt a lot better after talking to her and will be talking to her again. I also spoke to Lee in Tallahassee who gave me some advice and recommendations and it is so good to know there are people out there you can call when the going gets tough.

I want to talk to others who have lived with PF and would also like to talk to those who are just starting their battle. We do have strength in numbers. There may be times I need someone to lean on. There may be times you need someone to lean on. As long as we all walk this road together, we can all reach the finish line. Anyone who wishes to speak to me please do so by calling 407-832-1311 or write:

Guy Norsworthy
P.O. box 422, Loughman, FL 33858
NOTE: The following article was provided by the U.S. Food and Drug Administration (www.fda.gov). The illustration is by Sal Capo.

By Paula Kurtzweil
Public Affairs Staff, FDA

You don’t have to look far to find a health product that’s totally bogus—or a consumer who’s totally unsuspecting. Promotions for fraudulent products show up daily in newspaper and magazine ads and TV “infomercials.” They accompany products sold in stores, on the Internet, and through mail-order catalogs. They’re passed along by word-of-mouth.

And consumers respond, spending billions of dollars a year on fraudulent health products, according to Stephen Barrett, M.D., head of Quackwatch Inc. (www.quackwatch.com) a nonprofit corporation that combats health fraud.

Hoping to find a cure for what ails them, improve their well-being, or just look better, consumers often fall victim to products and devices that do nothing more than cheat them out of their money, steer them away from useful, proven treatments, and possibly do more bodily harm than good.

“There’s a lot of money to be made,” says Bob Gatling, director of the program operations staff in the Food and Drug Administration’s Center for Devices and Radiological Health. “People want to believe there’s something that can cure them.”

FDA describes health fraud as “articles of unproven effectiveness that are promoted to improve health, well being or appearance.” The articles can be drugs, devices, foods, or cosmetics for human or animal use.

FDA shares federal oversight of health fraud products with the Federal Trade Commission. FDA regulates safety, manufacturing and product labeling, including claims in labeling, such as package inserts and accompanying literature. FTC regulates advertising of these products.

Because of limited resources, says Joel Aronson, team leader for the nontraditional drug compliance team in FDA’s Center for Drug Evaluation and Research, the agency’s regulation of health fraud products is based on a priority system that depends on whether a fraudulent product poses a direct or indirect risk.

When the use of a fraudulent product results in injuries or adverse reactions, it’s a direct risk. When products do not cause harm but using it may keep someone away from proven, sometimes essential, medical treatment, the risk is indirect. For example, a fraudulent product touted as a cure for diabetes might lead someone to delay or discontinue insulin injections or other proven treatments.

While FDA remains vigilant against health fraud, many fraudulent products may escape regulatory scrutiny, maintaining their hold in the marketplace for some time to lure increasing numbers of consumers into their web of deceit.

The following products typify three fraudulent products whose claims prompted FDA to issue warning letters to the products’ marketers, notifying them that their products violated federal law.

**Two of the products also were**

**ONE PRODUCT DOES IT ALL**

“...extremely beneficial in the treatment of rheumatism, arthritis, infections, prostate problems, ulcers, cancer, heart trouble, hardening of the arteries, diabetes and more...” “completely eliminating the gout...” “...antiinflammatory, pain reliever...”

Be suspicious of products that claim to cure a wide range of unrelated diseases—particularly serious diseases, such as cancer and diabetes. No product can treat every disease and condition, and for many serious diseases, there are no cures, only therapies to help manage them.

Cancer, AIDS, diabetes, and other serious diseases are big draws because people with these diseases are often desperate for a cure and willing to try just about anything.

**PERSONAL TESTIMONIALS**

“Alzheimer’s Disease!!! My husband has Alzheimer. On September 2, 1998 he began eating 1 teaspoonful of... Pure Emu Oil each day. ... Now (in just 22 days) he no longer the goats, cleaned out the garage, seized the flower beds, and we tore the morning walk again. It hasn’t helped his memory much yet, but he is more like himself again!!!”

Personal testimonials can tip you off to health fraud because they are difficult to prove. Often, says Reynaldo Rodriguez, a compliance officer and health fraud coordinator for FDA’s Dallas district office, testimonials are personal case histories that have been passed on from person to person. Or, the testimony can be completely made up.

“...eliminates skin cancer in days...”

Be wary of talk that suggests a product can bring quick relief or provide a quick cure, especially if the disease or condition is serious. Even with proven treatments, few diseases can be treated quickly. Note also that the words “in days” can really refer to any length of time. Fraud promoters like to use ambiguous language like this to make it easier to finagle their way out of any legal action that may result.

**QUICK FIXES**

Product No. 1: Over-the-counter transdermal weight-loss patch

The FDA issued a warning letter to the marketer of the weight-loss product described here because it did not have an approved new drug application. Because of the newness of the dosage form—skin-delivery systems—FDA requires evi-
dence of effectiveness, in the form of a new drug application, before the product can be marketed legally.

**NATURAL**

"Healthy, simple, and natural—way to help you lose and control your weight."

Don’t be fooled by the term “natural.” It’s often used in health fraud as an attention-grabber; it suggests a product is safer than conventional treatments. But the term doesn’t necessarily equate to safety because some plants—such as poisonous mushrooms—can kill when ingested. And among legitimate drug products, says Shelly Maitland, a compliance officer and health fraud coordinator for FDA’s Denver district office, 60 percent of over-the-counter drugs and 25 percent of prescription drugs are based on natural ingredients.

And, any product—synthetic or natural—potent enough to work like a drug is going to be potent enough to cause side effects.

**TIME-TESTED OR NEW-FOUND**

"This revolutionary innovation is formulated by using proven principles of natural health based upon 200 years of medical science."

Usually it’s one or the other, but that claim manages to suggest it’s both a breakthrough and a decades-old remedy.

Claims of an “innovation,” “miracle cure,” “exclusive product,” or “new discovery” or “magical” are highly suspect. If a product was a cure for a serious disease, it would be widely reported in the media and regularly prescribed by health professionals—not hidden in an obscure magazine or newspaper ad, late-night television show, or Web site promotion, where the marketers are of unknown, questionable or nonscientific background.

The same applies to products purported to be “ancient remedies” or based on “folklore” or “tradition.” These claims suggest that these products’ longevity proves they are safe and effective. But some herbs reportedly used in ancient times for medicinal purposes carry risks identified only recently.

**SATISFACTION GUARANTEED**

"...Guarantee If after 30 days...you have not lost at least 4 pounds each week, your unopened check will be returned in..."

Here’s another red flag: money-back guarantees, no questions asked. Good luck getting your money back. Marketers of fraudulent products rarely stay in the same place for long. Because customers won’t be able to find them, the marketers can afford to be generous with their guarantees.

Product No. 3: Unapproved weight-loss product marketed as an alternative to a prescription drug combination

FDA issued an import alert for a Canadian-made weight-loss product whose claims compared the product with two prescription weight-loss drugs taken off the market after FDA determined they posed a health hazard.

**PROMISES OF EASY WEIGHT LOSS**

"Finally, rapid weight loss without dieting!"

For most people, there is only one way to lose weight: Eat less food (or fewer high-calorie foods) and increase activity. Note the ambiguity of the term “rapid. A reasonable and healthy weight loss is about 1 to 2 pounds a week.

**PARANOID ACCUSATIONS**

"Drug companies make it nearly impossible for doctors to resist prescribing their expensive pills..."

"It seems these billion-dollar drug giants all have one relentless competitive common fear constantly fear—natural remedies."

These claims suggest that health-care providers and legitimate manufacturers are in cahoots with each other, promoting only the drug companies’ and medical device manufacturers’ products for financial gain. The claims also suggest that the medical profession and legitimate drug and device makers strive to suppress unorthodox products because they threaten their financial standing.

"This [accusation] is an easy way to get consumers’ attention," says Marjorie Powell, assistant general counsel for the Pharmaceutical Research and Manufacturers of America. "But I would ask the marketers of such claims, ‘Where’s the evidence?’ It would seem to me that in this country, outside of a regulatory agency it would be difficult to stop someone from making a claim."

Think about this, too: Would the vast number of people in the health-care field block treatments that could help millions of sick, suffering patients, many of whom could be family and friends? "If flies in the face of logic," Barrett says on his Quackwatch Website.

**MEANINGLESS MEDICAL JARGON**

"Hunger Stimulation Point (HSP) ...thermogenics, which converts stored fats into soluble lipids..."

"One of the many natural ingredients is inulin/bestantocinate."

Terms and scientific explanations such as these may sound impressive and may have an element of truth to them, but the public “has no way of discerning fact from fiction,” Aronson says. Fanciful terms, he says, generally cover up a lack of scientific proof.

Sometimes, the terms or explanations are lifted from a study published in a reputable scientific journal, even though the study was on another subject altogether, says Martin Katz, a compliance officer and health fraud coordinator for FDA’s Florida district office. And chances are, few people will check the original published study.

"Most people who are taken in by health fraud will grasp at anything," he says. "They’re not going to do the research. They’re looking for a miracle."

**TRUTH OR DARE**

The underlying rule when deciding whether a product is authentic or not is to ask yourself: "Does it sound too good to be true?" If it does, it probably isn’t true.

If you’re still not sure, check it out: "Look into it—before you put it in your body or on your skin," says Reynaldo Rodriguez, a compliance officer and health fraud coordinator for FDA’s Dallas district office.

To check a product out, FDA health fraud coordinators suggest:

- Talk to a doctor or another health professional. "If it’s an unproven or little-known treatment, always get a second opinion from a medical specialist," Rodriguez says.
- Talk to family members and friends. Legitimate medical practitioners should not discourage you from discussing medical treatments with others. Be wary of treatments offered by people who tell you to avoid talking to others because "it’s a secret treatment or cure."
- Check with the Better Business Bureau or local attorneys’ general’s office to see whether other consumers have lodged complaints about the product or the product’s marketer.
- Check with the appropriate health professional group—for example, the American Heart Association, American Diabetes Association, or the National Arthritis Foundation if the products are promoted for heart disease, diabetes or arthritis. Many of these groups have local chapters that can provide you with various resource materials about your disease.
- Contact the FDA office closest to you. Look for the number and address in the blue pages of the phone book under U.S. Government, Health and Human Services, or go to www.fda.gov/ora/fed_state/dsfr_activities/dsfr_pas.html on the FDA Website.

FDA can tell you whether the agency has taken action against the product or its marketer. Your call also may alert FDA to a potentially illegal product and prevent others from falling victim to health fraud.

If you have comments or questions you can also call the FDA toll-free at 1-888-INFODFA or 1-888-463-6332.

Note: In addition, pemphigus and pemphigoid patients should avoid any product which enhances the immune system at their immune systems are already overstimulated. Such products may trigger a flare-up.

For those with Internet connections we suggest you visit the FDA website and discover the wealth of information available there. Those without a computer may find one at the local library.
Join the effort to establish an Office of Autoimmunity at NIH

NOTE: See "AARDANow! progress" on page six.

The American Autoimmune Related Diseases Association (AARDAN), a group of patient advocacy foundations of which the NPF is a member, endorses and supports passage of Rep. Waxman's bill (HR 2573, aka Senator Biden's bill in the Senate S1897) to establish an Office of Autoimmune Diseases at the National Institutes of Health. This is of utmost importance to the 50 million Americans who suffer from some form of autoimmune disease. An Office of Autoimmune Diseases would increase awareness, research, and education regarding autoimmune diseases.

As a disease category, autoimmune disease is the third most prevalent cause of disease in our country, following cancer and heart disease. Considering this fact, autoimmune diseases are significantly under-funded in the areas of research and education. We ask that, if you support this bill, contact your U.S. representative by letter, e-mail or a fax, asking him/her to cosponsor the bill. We need 150 cosponsors.

Take action today through Congress Connect which is available on the AARDAN website (www.aardan.org), through which you can send an e-mail, or even better, construct a letter in your own words to your representative.

Points to make in your own words:

• Autoimmune research is spread throughout all of the Institutes of Health, and is not the focus of any singular institute. This results in duplication and fragmentation of research efforts. An Office of Autoimmune Diseases would ensure that research dollars are spent efficiently.

• Autoimmune research collectively is significantly underfunded when compared to other disease groups, such as cancer and heart disease. Autoimmune diseases affect at least 5 percent of the population, cost $86 billion annually in health care costs, and yet autoimmune research is less than 3 percent of the NIH research budget.

• Mention your own experience with autoimmune diseases.

Ask your representative to cosponsor bill H.R. 2573 to create an Office of Autoimmune Diseases at the National Institutes of Health or ask your Senator to support the Senate version, S 1897. The time to act is now.

Date

The Honorable (your representative) United States House of Representatives Washington, DC 20515

Dear Representative:

I am writing as a constituent to urge you to cosponsor and support HR 2573 - The NIH Office of Autoimmune Diseases Act of 1999.

HR 2573 will establish an office of Autoimmune Diseases at the National Institutes of Health (NIH) that would conduct research and educational activities on autoimmune diseases through the national research institutes. The office would require only a modest annual operating budget as existing institutes will remain responsible for the actual research.

Autoimmune diseases are a broad category of related diseases in which a person's immune system attacks his/her own tissues. There are more than 80 known autoimmune diseases, including such well-known diseases as rheumatoid arthritis, lupus, multiple sclerosis, and scleroderma. The establishment of an Office of Autoimmune Diseases at NIH will ensure that research will be focused on the common factors that are prevalent in all autoimmune diseases.

[Insert personal information. This paragraph is an example.] I was diagnosed with one of the many autoimmune diseases, autoimmune hepatitis, six years ago; and most recently my eight-year-old niece was also diagnosed with the same disease. Currently there is no cure for our disease or any of the other potentially life-threatening autoimmune diseases. But with the passage of HR 2573, we will be one step closer to finding a cure for the 50 million Americans who suffer from autoimmune disease.

Thank you for taking the time to consider my views. I urge you to cosponsor and support this important legislation.

Sincerely,

Your Name Here

111 Your Street Yourtown, ST 54321 (301) 555-1212
How to calm the turbulent tummy

By Janet Segall

The digestion of food starts in the mouth. In the mouth, the saliva breaks the food up. The food then passes down into the stomach. In the stomach, enzymes are secreted to help in digestion. Some of the stomach contents are either digested out of the stomach or passed along into the intestines. The medications we take, Prednisone and the immunosuppressing drugs, pass through the stomach and are absorbed into the body through the intestines. These drugs can irritate the stomach lining, causing an upset stomach and nausea. Prednisone taken in any form can cause gastric or duodenal ulcers.

There are many drugs available in today's market that can help with the nausea and stomach upset. Some of those drugs are Zantac, Pepcid, Tagamet, and Pepto-Bismol. There are natural ways to help calm the stomach as well.

One of the best non-medicinal ways to help with stomach problems is ginger. You can buy ginger tea or ginger capsules from the health food store, or make your own tea from fresh ginger. Studies done with ginger showed that it was as effective as the leading over-the-counter motion sickness drugs in 90% of the people in the study.

Papaya is also believed to help calm the stomach and reduce stomach acids. You can get papaya tablets at the health food store, but fresh papaya is very tasty. It also contains essential vitamins and minerals, including Vitamin A and C, and is very high in potassium. Another suggestion to reduce stomach upset is not to eat three big meals a day, but rather cutting down to five or six very small ones.

Stress can be a major factor, because it can cause the excretion of excess stomach acids. Although it is pretty much impossible to completely rid oneself of all stress, because we are only human, and stress good or bad, plays a part in our lives. The real key is learning how to handle it and deal with it successfully. There are many ways now known to help deal with stress: meditation, yoga, Tai Chi, imagery, affirmations, biofeedback, slow deep breathing and moderate exercise (walking is great). The best way to use the deep breathing technique is to breath in through the nose while expanding your diaphragm, hold your breath for five seconds or so, and then breathe out through the mouth.

There are also many triggers to avoid which can work synergistically with the drugs to heighten stomach upset. Some of these are caffeine, aspirin, smoking, excess iron, milk, as well as some other dairy products. Although milk may buffer stomach acid for a short while, it actually stimulates stomach acid secretion. The best thing of course, is to listen to your body and it will tell you what works for you or doesn't.

Before following any of the suggestions above, check with your health care professional to make sure that the foods or supplements, or whatever you take, does not interfere with the medications.
Toronto celebrates successful first year

By Dan Goodwill
The Toronto Pemphigus support group held its most recent meeting on February 23 at the Toronto Memorial Community Centre. The group has now been meeting for over two years.

The group now seems to consist of two clusters of people. Most of the founding members continue to come to each meeting. All of these people have made significant progress over the past two years. One member of the group has now been off Prednisone (but still on Imuran) for a year. The others are on low dose Prednisone. Some are taking Cellept to supplement their Prednisone. Everyone in the group has ongoing, but relatively minor disease activity, primarily in the mouth.

The other segment of the group, who are relatively new to the disease, are experiencing much more serious disease activity. One individual has extensive blistering on his face and nose, and another has extensive blistering on his body. A third member of the group is experiencing a painful side effect, stenosis, which as explained to us is a loss of blood circulation in the hip causing a form of bone death. She was also experiencing tremors (shakes), which she subsequently found out were caused by a potassium deficiency. An endocrinologist has brought the tremor problem under control. The necrosis is a different matter. This has caused the dermatologist to re-evaluate the treatment regimen.

In two of the cases, a leading Canadian dermatologist is having difficulty bringing the disease activity under control. One individual has tried high dose Prednisone, pulse Cytoxan (cyclophosphamide) and high-dose intravenous immunoglobulin, without success. Much of the discussion this time focused on the need to reach out to the top experts in the world. While some Canadian doctors have considerable familiarity with the disease, their experience likely pales in comparison to the most experienced American doctors (e.g., Dr. Anhalt). The new members of the group were encouraged to seek higher level expertise if they are not making satisfactory progress.

One person in the group with serious disease activity has started taking modacare steriol, in essence because nothing else seems to be working. (Editor’s note: Pemphigus and pemphigoid patients should avoid any product which enhances the immune system as their immune systems are already over stimulated). The individual paid $42 Canadian (approx. $29 US) in a health store and is taking three tablets a day.

Another topic of discussion was the need for support and understanding from family and friends. It is clear that the disease takes its toll on both patients and their support group. All members of the group were encouraged to call each other, between meetings, to provide additional support.

Woodley discusses bullous diseases

By Carol Goren
There were 30 members and guests in attendance. Dr. David Woodley, USC dermatologist, was the speaker. He discussed bullous diseases. He listed the present therapies used for blistering diseases: colchicine, cyclosporine/neoral, intravenous immunoglobulin (IV), photopheresis, mycophenol mofetil, gene therapy, methotrexate, TNP & Nicotinamide.

He also discussed the difficulty with assessing the therapy for blistering diseases: rare diseases, small number of patients, diseases intrinsically wax & wane, lack of consistency with each therapy, reports are anecdotal & uncontrolled and difficulty in measuring epidermal adhesion of activity.

Finally, Dr. Woodley listed possible future therapies: gene therapy molecular methods to produce peptides that could block the t-cell receptor, anti-ideotopic antibodies and mononuclear antibodies that alter the immune response, autoantigen induction of tolerance-oral IV and protease inhibitors. Dr. Woodley also mentioned several new bullous diseases: P105 Pemphigoid, Antilaminin CP, IgA Pemphigus. The group had an opportunity to share and ask questions. The results of the National Fundraising Campaign was given: approximately $30,000 was collected with about $13,000 from the LA Chapter. The next meeting will be held in June, 2000. Members were asked to try to get speakers for future meetings.

Just a little reminder...

Personal profiles, like the one on page six, and other stories submitted for publication should be send as Word files or plain email. Photos must have good contrast and not be too dark. Get within 10’ of the subject to insure you are close enough. Photocopies or photos already printed (screened) will not work. Thanks.

How to donate to the NPF

- Cash/check outright contribution.
- Credit card contribution.
- Donation in the form of appreciated stock. This has a tax advantage for the contributor since the appreciated value is not taxed as capital gains tax and the full appreciated value of the donation is tax deductible. Janet Segall has the details for how to contribute stock. See page two for contact information.
- Matching grant contribution from employer. Donors should check with their employer to see if there is a matching grant program and what the terms are.
- Legacy—Anyone who wants to can name the Foundation in their will.

Janet Segall is available in the NPF office to answer any questions you may have.
Dallas meeting covers wide range of topics

By Angela Vickers

The Dallas/Fort Worth support group meeting was held on February 26 at the Eldorado Country Club in McKinney. We were very happy to have Janet Segall and Dr. Amit Pandya, Associate Professor, University of Texas, Southwestern, Dermatology Dept.

This meeting was prompted by the mother of a three year old who was recently diagnosed with PF. Her talks with Janet brought Jan to the Dallas area, and the meeting was organized. Most people were under the impression this was a disease of the middle aged. It was a surprise to hear of children so young having pemphigus. Janet and the boy’s mom, Meredith thought that a picture of the toddler suffering from PF might bring more attention to pemphigus at the next AAD meeting in San Francisco.

There was a large amount of information discussed during the meeting. Some of the topics covered were treatments, differences of opinions from some physicians regarding treatments such as gold therapy, many of the side effects from the use of long-term Prednisone and medications, such as diabetes, high blood pressure and osteoporosis. One husband told us of the success his wife had on Fosomax. She went from a diagnosis of osteoporosis to osteopenia. The biology of pemphigus was discussed.

We are planning another meeting in May or June depending on the availability of our speaker.

San Francisco chapter schedules a barbecue

The San Francisco chapter will meet Saturday, May 13, at Elke Wittenberg’s home in Foster City. A casual barbecue and pot luck are planned. Members are invited to bring a dish and participate in conversation with fellow pemphigus patients. No speaker is planned at this time.

Those interested are requested to RSVP by phone or email to Elke Wittenberg, 650-574-1334 or elke65O@aol.com. Her home is located at 1019 Pensacola Street, Foster City, on the western end of the San Mateo Bridge.

National Pemphigus Foundation

Income statement for the 12 month period ending December 31, 1999.

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TOTAL Income from operations 33,039.68 33.7
Earnings before income tax 33,039.68 33.7
Net income (Loss) 33,039.68 33.7

Current assets 77,320.73
Checking account 35,798.29
New account 41,462.44
 Petty cash 60.00

TOTAL current assets 77,320.73

Fixed assets 4,488.27
Equipment 5,289.17
Accum depreciation (800.00)

TOTAL fixed assets 4,488.27

TOTAL assets 81,809.00

TOTAL liabilities 5.00

Equity 81,809.00

Retained earnings - prior year 48,769.32
Retained earnings - current year 33,039.68

TOTAL equity 81,809.00

TOTAL liabilities and equity 81,809.00

NPF SUPPORT GROUPS

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Online
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Email: bmaizy@earthlink.net

Website
www.pemphigus.org
webmaster@pemphigus.org
Instructions: Find the words listed on this page. Words may be forward, backwards, up, down or diagonal.
Get the patient to the medication while avoiding the pemphigus antigens. (You didn't know antigens were so cute, did you?)

Got questions?

We have answers. In fact, we have answers to questions you haven't even thought to ask yet. We spend our time and energy rounding up the latest news and information on pemphigus and pemphigoid so you don't have to. And, we provide it to you in terms you can understand and use. Only the National Pemphigus Foundation covers these subjects so thoroughly! Sign up today!

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Copy or cut out this form, print clearly, and return with donation to:
The National Pemphigus Foundation
P.O. Box 9606, Berkeley, CA 94709-0606.

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Spring in Washington D.C. means it's time for NIAMS

On February 29 and March 1, 2000, Executive Director Janet Segall represented the NPF at the annual NIAMS Day meetings.

NIAMS, the National Institute of Arthritis, Musculoskeletal and Skin Diseases, a division of the NIH, hosts a gathering of the member organizations of the Coalition for Patient Advocacy for Skin Disease Research (CPA-SDR). The idea is to hear about NIAMS, discuss common goals on the first day, and visit with lawmakers on Capitol Hill the following day.

Dr. Stephen Katz, Director of NIAMS, answered questions regarding NIH and NIAMS funding of skin disease research. He also led a tour of the skin disease research facilities at the NIH.

The proposed Office of Autoimmunity was one of the hot topics discussed among those attending. (See story on page ten).

In regard to clinical research, Dr. Katz reiterated his belief that the majority of the money spent must go toward basic research, and that is the first priority of NIAMS. He also believes that it is important to invest in the training and development of upcoming clinicians. He explained that money is, and has been, allocated toward those goals.

The skin research division of NIAMS traditionally gets less money for research than other divisions. Dr. Katz discussed his meeting with the Herzog Foundation about the development of a partnership between the foundation and NIAMS. It is hoped that this will lead to the funding of epidemiology studies in the future.

On March 1, the members paired up with physicians to hike up to Capitol Hill and speak with lawmakers about NIAMS and SPA-SDR concerns. The day began with a breakfast at which Representative John Porter (R-IL) was given a Public Service award for his commitment to NIH.

Janet Segall was teamed up with several physicians from the Society of Investigative Dermatology (SID), including NPF Medical Advisor Dr. Luis Diaz, and Dr. Russell Hall, who is treating pemphigus and pemphigoid patients at Duke University in North Carolina.

The group then visited with several Senators and Representatives to encourage them to support an increase of 15% for the NIH. This is the second of a three-year plan to double the NIH budget in five years. The NIH has successfully received an increase of 15% for these last two years.

L to R: Vicki Kalabokes, CEO of the Alopecia Areata Foundation; Dr. James Wilson of SID; Janet Segall and Dr. Luis Diaz.