Historic conference draws near

NPF Medical Advisors prepare for their worldwide conference at NIH on why pemphigus is important in the study of autoimmune disease.

Clinton signs legislation

Federal legislation creates Autoimmune Diseases Coordinating Committee.

Prednisone

Everything you need to know about the drug we love to hate.

Medic Alert

When you can’t speak for yourself this bracelet can save your life.

Autoimmunity

The basics you need to understand the system.

Help yourself

Ms. Jonnie Dale explains how to get back to basics.

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The Organizing Committee includes (l-r) Drs. Jean-Claude Bystryn, Grant Anhalt, Luis Diaz, and John R. Stanley.

NIH Meeting Brings Together World Experts on Pemphigus

On April 20-21, scientists and clinicians from around the world will meet at the National Institutes of Health, Bethesda, Maryland, for a two-day conference: “Pemphigus as a Model of Organ-Specific Humoral Autoimmune Diseases.”

The conference is co-sponsored by The National Pemphigus Foundation and The American Autoimmune Related Disease Association. Organized by NPF Medical Advisory Board Members Drs. Jean-Claude Bystryn, Grant Anhalt, Louis Diaz, and John Stanley, the meeting will bring together scientists conducting basic research on autoimmunity with researchers studying pemphigus. The goal of the meeting will be to review the current understanding of the causes and treatments of autoimmune diseases in general, as well as discuss the specifics of pemphigus.

Pemphigus is a classic example of an autoantibody mediated disease. It provides an excellent model for the study of the mechanism and treatment of autoimmune diseases in general. By bringing together experts on autoimmune diseases with experts on pemphigus the conference organizers hope that new a understanding of the etiology, pathogenesis, and therapies for both pemphigus and other autoimmune diseases will emerge.

The conference will include workshops on topics including: The etiology of autoimmune diseases; The pathogenesis of pemphigus; Current and novel treatments for pemphigus; Future treatments for pemphigus. In addition there will be a poster session on the evening of April 20 to permit the presentation and discussion of recent advances in the field. In addition to the organizing physicians, presenters will include: Dr. Masayuki Amagai, Keio University School of Medicine, Tokyo, Japan; Dr. Livia Cacciola-Rosen, Johns Hopkins Medical Center; Dr. Pamela Cowin, New York University Medical Center; Dr. C. Garson Fathman, Stanford University School of Medicine; Dr. Takashi Hashimoto, Kureme University School of Medicine, Fukuoka, Japan; Dr. Robert E. Jordan, University of Texas Medical School; Dr. Stephen I. Karz, NIH; Dr. M. G. Mahoney, Thomas Jefferson University; Dr. Alan N. Mosshell, NIH; Dr. Hosssein Nousari, Johns Hopkins University Medical Center; Dr. Joyce Rico, Fujisawa Healthcare; Dr. Noel Rose, Johns Hopkins University Medical Center; Dr. John R. Stanley, University of Pennsylvania; Dr. Victoria Werth, University of Pennsylvania.

“This is an exciting meeting,” states organizing committee member Dr. Bystryn. “It’s the first international conference on this important disease, which is open to all investigators in the field. We hope it will lead to new discoveries and better treatments that will help patients with this serious disease.”

The conference is supported by a grant from the National Institute of Arthritis, Musculoskeletal and Skin Diseases, National Institutes of Health. Additional support has been provided by Pepthimmune, Inc., a subsidiary of Genzyme, Inc., and Fujisawa Healthcare.

Annual Fund Drive a Huge Success

The 2000 Annual National Pemphigus Foundation Fund Drive was a huge success. Thanks to your generosity and the generosity of your families and friends, the Foundation is starting 2001 with more financial security than ever before.

“I applaud the personal efforts made on the Foundation’s behalf,” said Janet Segall, Executive Director. A full accounting of the Foundation will be presented in the next issue of the Quarterly. Please turn to page 14 for a list those who supported us this year.
The right to be heard—Your voice is important

With a new Administration in Washington, I want everyone to keep in mind that as citizens of this country we have our right to be heard. There are many important issues being discussed that will effect all of us with pemphigus/pemphigoid disease - health care issues, research issues, money issues, etc. Let your representative both in the House and Senate know what your positions are on these important matters. Your voice is an important one. If you want to contact your person in Congress they are up on the web at www.house.gov and www senate.gov.

If you are not on the Internet, each representative has a local office that you can contact to find out the Washington office number, or fax. Several years ago, I had a health care issue. I contacted my local representative office and explained the problem. They were very helpful and the issue was resolved promptly. They are there to help you. Let them.

Every year, we learn more about patient’s needs. As you all know, this year, we are having a special conference on pemphigus at the NIH in Bethesda, MD. On the second day of this conference, I will be called upon to address doctors and researchers with your questions and concerns. I would like for you to let me know what problems are the most troubling to you - what is that you would like me to tell them. We have many terrific doctors treating and researching pemphigus/pemphigoid. Although this particular meeting is only on pemphigus, I believe that there are similar concerns about both diseases that I could bring to them. I find it very encouraging that at this meeting, the doctors are interested in what we think as patients. So, write, email, or call me at the office with your concerns and I will bring them to the meeting.

I would like to thank everyone who contributed to this year’s holiday fundraiser and to those who have contributed throughout the year. I also wanted to thank all those volunteers who have given their time to helping the Foundation, and to helping others who are learning to live with pemphigus/pemphigoid disease: our discussion group, our support group leaders, and the volunteers in the Heart to Heart section of the newsletter, as well as our volunteer Board of Directors and discussion group Administrator. Having all these wonderful people on board makes this journey worthwhile.

We lost some people this past year and I want to send along my condolences to all those who lost a loved one. Along with tragedy, we had a few joyous celebrations. Sandra & Herb Feldstein celebrated their 50th anniversary. Francesca (with PF), 16 years old, started a Foundation to help other kids with skin diseases and had a very successful first duck race fundraiser. In spite of the chemotherapy drugs she was on, Erica and Tyson had a wonderful, healthy baby girl. Many friends have found good control after long battles on heavy doses of drugs.

I have hope. The success stories I hear give me hope. I believe that even without a cure or better drugs, we are strong and can fight this battle against these diseases, find those things in the world that can help us like reducing stress or learning to manage our stress better. Learning which foods work for us so we might help reduce the size of a flare. Asking your family and friends for support when you need it. Getting involved in your community or help the Foundation with a fundraising event. With hope, we can move forward into the future. I wish everyone good health in the New Year!

Janet Segall
Executive Director
Working together, united in hope

By Jean B Barish
NPF President

During the past six years I have had the joy of watching the National Pemphigus Foundation grow from a small, unknown organization to one with a national, and more recently, an international presence. We are reaching a growing number of patients with pemphigus and pemphigoid who come to us for medical and emotional support. We have also had very successful patient-doctor conferences, strengthened ties with the pemphigus community in England, and we are about to host an international conference at the prestigious National Institutes of Health. The growing pains of the past are behind us. We have taken our baby steps. We are now ready to begin to move into the larger world.

As we enter our next phase we are reaching out more and more to other healthcare organizations. There are several stories in this issue highlighting this new growth. We were represented at a recent meeting of the American Autoimmune Related Diseases Association, and we recently attended the National Health Council’s Voluntary Leadership Conference. Additionally we will have a presence at the upcoming American Academy of Dermatology meeting in Washington, D.C., and we remain actively involved with the Coalition of Patient Advocates for Skin Disease Research.

Our connections to these other organizations is important to us. Through cooperation and communication with other groups we can have a bigger impact on meeting the needs of people with pemphigus. By supporting each other in legislative activities, research, and educational programs we can all benefit.

Additionally, and perhaps most important, it is comforting to know that the hopes of people with pemphigus...hopes for better treatments, better medical care, and eventually, a cure...are shared by others from organizations small and large. Being a part of a larger groups that, like ours, dreams of the day when anyone with a serious illness will be free of fear, pain, and anxiety gives all of us support and strength.

I hope you share my enthusiasm in joining with others. While the Foundation will always remain unique and dedicated to helping people with pemphigus and pemphigoid, we can also enter the larger health care community. I believe that through cooperation with other groups we can become bigger and stronger. We can learn from each other, teach each other, and support each other in our common battles. By joining together we can have a louder voice, that when spoken in unison will be heard by all.

Autoimmune diseases coordinating committee now established at NIH

Federal legislation, recently signed into law by President Clinton, provides for the creation of an Autoimmune Diseases Coordinating Committee within the National Institutes of Health, Title XIX of the Children’s Health Act 2000 states that “...The Director of NIH shall expand, intensify, and coordinate research and other activities of the National Institutes of Health with respect to autoimmune diseases.”

The legislation spells out a step-by-step plan for this coordination of activities and for allocation of funds for the study of autoimmune diseases.

The Autoimmune Diseases Coordinating Committee will be composed of representatives from all Institutes within NIH involved in research related to autoimmune diseases, as well as representatives from other Federal departments and agencies involved with such diseases, including the Centers for Disease Control and Prevention and the Food and Drug Administration.

The Chair of the Committee will report directly to the Director of the NIH. Prior to this legislation, research efforts on autoimmune diseases within NIH were fragmented and, possibly, duplicative. Until now the research has been specialized and focused more on a particular disease, not on autoimmunity in general.

The newly created Autoimmune Diseases Coordinating Committee is an effort to break down barriers between specialties and create a more open environment that will facilitate the exchange of information and ideas between all those scientists working on different pieces of the puzzle of autoimmunity. The Committee will be a forum where research related to all autoimmune diseases will be presented, discussed, and evaluated.

Through this collaboration and cooperation it is hoped that scientists will reach a better understanding of the underlying causes and mechanisms of all autoimmune diseases.

This legislation is very important in advancing autoimmune disease research. It helps focus attention on the broad category of autoimmune diseases, and, hopefully, will increase funding and research efforts in this area.

The American Autoimmune Related Disease Association, was the leading organization advocating for Title XIX. The NPF would also like to thank all of our members who took the time to write to their representative asking for their support of this legislation.

No doubt communication from those most directly impacted by an autoimmune disease helped convince the legislators of the importance of this bill.

In the coming months AARDA will continue its efforts by working closely with NIH to facilitate the creation and activities of the Committee. The NPF will be supporting AARDA in these efforts. The legislation was initiated in the House of Representatives by Rep. Hanry A. Waxman and Rep. Constance A. Morella, and by Senator Joseph Biden, Jr. of Delaware.

Also working on behalf of this legislation were Rep. Michael Bilirakis, Sen. Edward Kennedy, and Sen. William Frist. We are grateful to these legislators, and all the others who voted in support of this bill.
Affiliations provide stronger voice

From time to time we have written about other organizations with which the NPF is affiliated. These affiliations have strengthened us and have given us a voice in the larger health-care community.

Three important affiliations are with the American Autoimmune Related Diseases Association, Inc. (AARDA), the Coalition for Patient Advocacy for Skin Disease Research (CPA-SDR), and the National Health Council (NHC).

The American Autoimmune Related Diseases Association, Inc. is dedicated to the eradication of all autoimmune diseases through education, research, advocacy, public awareness and patient support. Its founder and Executive Director, Virginia Loddo, started AARDA in the belief that more attention should be focused on autoimmune diseases in general.

AARDA is the only national organization dedicated to addressing problems common to all autoimmune diseases. To advance their mission of raising public awareness of autoimmune diseases, AARDA sponsors physician's conferences, research, legislative advocacy, and an annual awareness campaign. We are pleased that AARDA is co-sponsoring our April conference to be held at NIH, "Pemphigus as a model of organ-specific humoral autoimmune diseases."

AARDA actively advocates for all patients with any autoimmune disease. They have provided testimony to various governmental agencies, advocated in support of orphan drug tax credits to encourage research and development of drugs for rare autoimmune diseases, and supported patients' rights legislation.

Most recently AARDA worked closely with Congressional legislators to provide for an autoimmune Diseases Coordinating Committee within the National Institutes of Health. (See page three of this issue for the complete story.) All of these efforts focus on the issues shared by all people with autoimmune diseases, and bring these issues to the attention of the public and policy-makers.

AARDA has organized a National Coalition of Autoimmune Patient Groups to help bring a more unified voice to the problem of autoimmune diseases. In addition to the NPF, this coalition has members representing a variety of autoimmune diseases, including arthritis, kidney disease, Crohn's disease and colitis, and scleroderma. Through regular meetings and communications, the coalition helps AARDA in its efforts to raise public awareness and support for autoimmune diseases.

AARDA has helped give everyone with an autoimmune disease a stronger, more unified voice. More information about AARDA is available on their web-site at: www.aarada.org.

The Foundation is also affiliated with the Coalition of Patient Advocates for Skin Disease Research (CPA-SDR), often referred to by the NPF as "The Coalition." This is a voluntary coalition of many organizations representing people with skin diseases throughout the United States and the world.

The CPA-SDR supports basic science and clinical research, disseminates information to patients and professionals, fosters public education and awareness of skin disorders, and addresses patient care.

The CPA-SDR works closely with the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) within the National Institutes of Health to coordinate research efforts for all skin diseases. One of its most important activities is an annual meeting of Coalition members with representatives of NIAMS, followed by meetings with members of Congress to educate and inform our lawmakers about the importance of skin disease research and the impact of skin diseases on our society.

At least one NPF representative attends this annual meeting. The Coalition also works closely with two affiliate members the American Academy of Dermatology (AAD) and the Society for Investigative Dermatology (SID), to increase skin disease research and coordinate patient care issues.

The collective efforts of the CPA-SDR are of vital importance in advancing the cause of people with skin diseases, including pemphigus and pemphigoid. Through its efforts research supported by the NIH and coalition member organizations has made great progress, discovering the genes for several skin diseases, new proteins, new drug delivery systems, new immunology-based treatments, and increased understanding of the genetic and cellular mechanisms involved in skin diseases.

The Foundation's most recent affiliation is with the National Health Council. The National Health Council is a nonprofit umbrella organization comprised of over 100 member organizations committed to quality health care. The Council's constituency includes some of the country's leading voluntary health agencies, including the American Cancer Society, the American Diabetes Association and the Arthritis Foundation, as well as numerous smaller organizations. These member organizations serve over 100 million people with chronic diseases and/or disabilities. The Council's member organizations also include professional associations, managed care, biotechnology organizations and pharmaceutical companies.

The Council's mission is to promote the health of all people by advancing the voluntary health movement. This movement is "driven by volunteers who work together toward the prevention, treatment, and cure of diseases and/or disabilities.

Through communication, collaboration and consensus, the Council's member organizations can achieve their objectives more effectively than they could alone. By leveraging the collective resources of its member organizations on important areas of agreement, the Council helps forge positions that are thoughtful, creative and strongly supported.

Through a variety of programs Council supports research, patient services, public education, community service, patient advocacy and professional education. For more information about the National Health Council and their programs visit their website at: www.nationalhealthcouncil.org.

The NPF is pleased to be affiliated with the National Health Council. We believe they will help us further our goals and give us an important voice in the health care community.
NPF welcomes new Medical Advisory Board members

The National Pemphigus Foundation is pleased to welcome Dr. Sergei Grando and Dr. Hossein Nousari to the Medical Advisory Board.

Dr. Sergei Grando is Professor of Dermatology, at the Department of Dermatology, University of California-Davis. Dr. Grando was born and educated in Kiev, Ukraine. He received his M.D. from the Medical Institute, Kiev in 1980; a Ph.D. in Pharmacology and Biochemistry from the Post Graduate Institute for Physicians, Kiev and a Doctor of Science (D.Sc.) degree in Immunology and Cell Biology from the Central Institute of Dermatology and Venereology, Moscow.

He then became Dean, International Relations, at the Medical Institute in Kiev. This allowed him to freely travel to Western countries and meet with numerous academics. In May, 1991, just before the fall of the Soviet Union, Dr. Grando, his wife and two small children traveled to the U.S. for a meeting with Dr. Peter Lynch, then Chairman, Department of Dermatology, University of Minnesota School of Medicine. With Dr. Lynch's help, Dr. Grando sought asylum in the U.S. He has been here ever since, becoming an American citizen.

Dr. Grando worked at the University of Minnesota until 1996 as an Associate Professor of Dermatology. He then joined the Department of Dermatology at U.C., Davis, where he continues to work.

Dr. Grando's research focuses on non-steroidal treatment of pemphigus and other bullous diseases. As a physician he is deeply concerned about the effects of the drugs currently used to treat pemphigus, and is devoting his research efforts on finding alternatives to current therapies. Dr. Grando has authored over 200 scientific articles, has been the recipient of research grants from the NIH and other granting organizations, and has been a featured speaker at numerous national and international meetings.

Dr. Hossein Nousari is Assistant Professor of Dermatology and Medicine and Co-Director of Immunodermatology, Johns Hopkins Medical Institutions. He was born in Cordoba, Argentina, where he received his medical training at Catholic University of Cordoba in 1989. He was trained in Internal Medicine and Rheumatology in Argentina before moving to the United States.

In 1994 he moved to the U.S. and began working at Johns Hopkins University, Baltimore, in the Division of Dermatoimmunology. Following an internship at George Washington University Hospital, School of Medicine, Dr. Nousari returned to Johns Hopkins, where he continues to work.

Dr. Nousari's research focuses on developing more effective immunosuppressive therapies for autoimmune skin diseases, including pemphigus and pemphigoid. He has published widely in textbooks and medical journals. He also lectures widely in the U.S. and overseas.

Dr. Nosari has a clinical practice devoted to autoimmune skin disorders, treating patients with pemphigus, pemphigoid, lupus, scleroderma, vasculitis, and dermatomyositis. Because he is familiar with the cultures of Latin America and Spanish is his native language, many of Dr. Nousari's patients are from the Hispanic community. He consults widely by telephone and internet with Spanish-speaking patients as well as with physicians from Latin and South America.

Dr. Nousari has been very helpful to the NPF in supporting its efforts to reach the Spanish-speaking community.

NPF Attends Leadership Conference

On February 8-10, NPF President, Jean Barish and Executive Director, Janet Segall attended the Voluntary Health Leadership Conference sponsored by the National Health Council.

The National Health Council is an umbrella organization whose members represent the entire spectrum of health issues.

The conference brought together staff and volunteer leaders from over 20 organizations, large and small, to learn, share experiences, and help direct the Council's agenda for the coming year. In addition to the NPF, representatives from the American Cancer Society, the American Diabetes Association, and the American Heart Association also attended. Speakers came from academia, health care organizations, and policy research organizations, including Harvard University, the Epilepsy Foundation of America, and strategic health policy International.

The agenda included such topics as: "Front Line Research: Healthcare Quality and Delivery," "Advocacy Activities For 2001," and "Creating a Global Patient's Voice." A highlight of the conference was a meeting with leaders from RAND Health, which is the nation's largest private health care research organization. It has helped shape private and public sector responses to emerging health care issues for three decades. The Foundation's attendance at the conference was sponsored by the National Health Council. A full report of the conference will be in the next issue of the Quarterly.
When you can’t speak for yourself, this bracelet might just save your life

Imagine you have a medical emergency that renders you unconscious or unable to communicate. You also have a chronic illness and you are taking one or more prescription medications, medications that could adversely interact with other drugs, or, as is the case with Prednisone, medication that reduces your body’s natural ability to deal with the stress of a medical emergency.

Who will speak when you can’t? When the call for help comes, emergency personnel need information. It must be fast and it must be accurate. Your life is on the line.

All too often, however, because of the nature of the emergency, accurate information is difficult or impossible to come by. The result could be improper or inadequate care that could have serious, life-threatening consequences.

Imagine, instead, that emergency responders had immediate access to your important medical information, such as the fact that you have pemphigus and are taking Prednisone and Imuran, as well as access to physician and family contact information.

With this critical information it is easy to imagine how much more effective and less risky emergency medical treatment could be. For people suffering from a chronic illness such as pemphigus this information could make all the difference between adequate and inadequate emergency care.

MedicAlert® is an organization that provides the lifesaving information that could make the difference. Founded by Dr. Marion and Chrsissie Collins of Turlock, California, after their daughter almost died accurate treatment that could save your life. MedicAlert® has more quality of care in a medical emergency, but also member confidentiality and appropriate

From an allergic response, the MedicAlert Foundation provides emergency medical personnel with potentially lifesaving information.

The MedicAlert® service is a lifeline. Members provide information regarding their medical conditions and medications, physician(s) and family contacts in order to build their MedicAlert® file.

They then receive a membership card, access to the MedicAlert® 24-hour Emergency Response Center, and, most important, an emblem they can wear as a bracelet or necklace engraved with their personalized membership number and their primary medical condition.

The MedicAlert® logo is recognized by emergency responders around the world. When they see that emblem engraved with your personal ID number and essential medical condition, they call the MedicAlert® 24-Hour Emergency Response Center, which transmits vital medical facts that help you receive the fast, than 2 million members in the United States and an additional 1.5 million worldwide.

The heart of the service is a 24-hour Emergency Response Center, staffed by teams of specially trained nurses and other professionals around the clock, 24/7/365.

Many MedicAlert® members have credited the information communicated by their emblem and the Emergency Response Center with helping to save their life. Many others say MedicAlert helped deliver faster or better treatment during a medical crisis.

MedicAlert® has received endorsements from such prestigious organizations as the American College of Emergency Physicians; Emergency Nurses Association; and, American Hospital Association. NPF Medical Advisory Board Chairman Dr. Grant Anhalt also highly recommends MedicAlert®, as does Executive Director Janet Segall.

Not only is the quality of the information provided by MedicAlert® important for saving lives and improving the use of member’s medical records is assured.

As a matter of strict policy backed by comprehensive procedures and technology, member information is closely protected by MedicAlert®, and is never shared for business purposes with any other organization or company.

Moreover, as a nonprofit organization, MedicAlert®, is not commercially motivated or tax-subsidized, where such factors as profit requirements, stock price, bureaucracy or political concerns can lead to competing or overriding issues.

Membership in MedicAlert® is available to anyone interested in the protection provided by emergency medical information or who needs to have something known in an emergency if they are not able to speak clearly.

To learn more about MedicAlert® or to enroll as a member, call 1-800-432-5378 or visit their website at www.medicalert.org. A small effort today can make a big difference tomorrow.
Things we can do to help ourselves and others

By Jonnie Dale

The name pemphigus vulgaris comes from the Latin word, vulgar meaning “common” and the Greek word pemphigus meaning bullous or boil. Although pemphigus vulgaris is a rare condition; it is the most common of the several types variants. It is similar to pemphigus foliaceous and treatments are similar as well.

Pemphigus is not contagious. We still do not know exactly what causes it and it’s an autoimmune disease, which means that the body is attacking itself. It is generally manageable. Complications rise from cases of missed diagnosis and proper treatment. Many General Practitioners are not familiar with symptoms and patients who would otherwise be undergoing treatment, spend months, sometimes years, searching for proper treatment. Added to the mystery is the fact that everyone responds a little differently to various treatments and stages of illness.

Prednisone is the most common steroid prescribed for treatment. It is not the kind that builds muscles, but instead zaps bone and muscle tissue. It suppresses the immune system and actually prevents the adrenal glands from functioning. Prednisone may keep the symptoms at bay for long periods of time, but it presents difficult side effects. (See Prednisone, page eight.)

Zantac or Ranitidine are usually prescribed when undergoing steroid treatment to help prevent ulcers and general stomach distress. Calcium is also depleted on steroid therapy and therefore patients typically take about 1600 mgs of calcium with vitamin D daily. Fosamun is a drug often prescribed to prevent bone loss.

It is recommended that patients on high dosages of steroids for long periods of time use a diet of no, or low amounts of, salt and sugar. The book, Coping with Prednisone by Zaksman and Ingelfinger, discusses this at length. The authors feel that avoiding these foods help to reduce the possible debilitating side effects of long-term steroid usage. Try not to get depressed, surrounding oneself with positive company and letting family members know that there must be no negative vibes flying about. It helps amazing changes can happen.

Pemphigus is treatable in almost all cases and remissions do occur. This is encouraging! Complete remission is defined differently from clinical remission. Clinical remission is defined as determining the maintenance dosage of steroids to keep the body from presenting symptoms. Complete remission is total withdrawal of all steroids and having no symptoms. There is one person who was in complete remission for 25 years.

Awareness - Doctors, dentists cannot be aware of every ailment under the sun. Promote, and be an advocate for, sharing knowledge among lay persons and professionals. Respect professionals who say that they don’t have a diagnosis and be thankful that they are continuing to take tests. Maintain a calm and persevering attitude.

Support Groups – Continue supporting one another in your homes, in your local community, and on a national and international level. There are valuable support systems already in place for folks with pemphigus. The NPF has many ways to help including this newsletter, an online support network, local support groups in a dozen cities and a website with all kinds of helpful information. There is also an annual doctor/patient conference where some of the best researchers on pemphigus present the latest information about treatment.

Caregivers – Caregivers need to be educated to soothe and care for the patient. Caregivers should try to take time out to care for themselves too. They can also reduce the stress of taking care of a patient. Caregivers need help, too, about half of all patients use antidepressants.

Health Insurance – Understand the need for your family’s protection and for the protection of others. Support organizations that support healthcare. Sometimes it is necessary to keep their insurance company to get the benefits you deserve. You need to apply for disability, they do it often takes perseverance, sometimes over the course of years. Asking for assistance might be difficult, but it is important.

Oral Hygiene – Clean teeth after all meals. If anything feels or sandpaper in an unusual manner, check on it. Pemphigus patients are often sensitive to various foods. Keep a food diary and look for patterns.

Check your body regularly for unusual characteristics and inform your doctor of changes. Support creative methods of honoring the body’s intuitive ways of healing. Study your disease and your body. Do what is right for you.

Promote positive healing energy everywhere. Be kind and patient, we’ve all got our internal battles going on. Go inside and find your answers. They are within you.

Take care of yourself with affirmations, quiet meditation, good food and good company. Ask for help with anxiety-producing activities, paying bills, etc. Journal your drug dosage and responses. You may wish to include your emotions. Many believe that stress may cause or worsen flares.

Eat regularly planned meals in a relaxed environment. When I was at my worst, home-made soups, tofu, fresh green vegetables, herbal teas, filtered water and juice were my comfort. Baked apples have been a deliciously sweet nutritious dessert. Avoid acidic foods (tomatoes and orange juice) and alcohol and caffeine.

Smoothes – (fresh fruit, soy milk or dairy milk, soy protein powder mixed in a blender) are great for taking medications with, and they provide daily nutrition. They can also satisfy a sweet tooth. Baby food or a blender can help those who have trouble with whole foods. Carry a wide bendable straw with you if you can’t eat solid food. If you are sensitive to garlic and onion and leeks, as are some pemphigus patients, avoid restaurant food which may have ingredients event he waiters don’t know about. Daily vitamins really help, including a good multivitamin. Be careful of herbal supplements that may affect the immune system (i.e. Echinacea). You definitely do not want anything that will strengthen an already over-active immune system.

Cleanliness – Daily baths, steams or sauna are relaxing and cleanse the skin in and out. When I couldn’t use my regular shampoo because it stung too much I tried [&] Baby Extra Sensitive Shampoo and it worked wonders.

Walk as often as you can. Sometimes it can be difficult to be motivated or to work through the achy joints, but try to every day. A little bit of sun is okay, but too much is not good.

Above all else, keep a positive attitude. You will never get better if you don’t think you will. Pemphigus is manageable.
What you need to know about Prednisone

Prednisone is the drug of choice for treating pemphigus and pemphigoid. It is a synthetic form of the naturally occurring steroid hormone cortisone. Cortisone, produced in the adrenal glands, helps reduce inflammation, regulates salt and water balance, affects the immune system and helps the body withstand stress. Prednisone, like cortisone, acts as a powerful anti-inflammatory. Prednisone, the generic form of the drug, is also marketed as Deltasone®, Meticorten®, Orasone®, and SK-Prednisone®. Prednisone should not be confused with the dangerous anabolic steroids used by weight lifters to increase muscle mass.

Prednisone was originally hailed as a “miracle drug”. Before its use started in the 1950’s, the life expectancy of a person with pemphigus was about 5 years. Now, thanks largely to Prednisone, pemphigus is rarely fatal. However, prolonged use of Prednisone can have many undesirable side effects. The risk of side effects generally depends on the amount and length of time the drug is taken. Proper management of pemphigus and pemphigoid, therefore, requires proper management of the side effects of Prednisone. The more you know about Prednisone the easier it will be for both you and your physician to treat your disease. The side effects of Prednisone are:

Weight Gain. Increased appetite and weight gain are seen by almost everyone taking Prednisone. Prednisone can also cause a puffy, or “moon face,” and a fatty deposit on the abdomen and the back of the neck, sometimes referred to as a “buffalo hump.” Following are suggestions for minimizing the weight gain problems associated with Prednisone:

- Avoid simple sugars. Simple sugars in foods like candy, cakes, and cookies are digested too quickly and leave you hungry.
- They can also be a problem if you have a history of “borderline” diabetes. Choose foods with complex carbohydrates such as rice, beans, and high fiber cereals. They take longer to digest and satisfy your hunger much more effectively.
- Pay attention to fat. Fat has over twice the calories per gram than proteins and carbohydrates. By reducing the fat in your diet you reduce calories. But be careful not to eliminate the “good” omega-3 and omega-6 fats found in fish such as salmon, sardines, and tuna (omega-3) and whole grains and walnuts (omega-6).
- Reduce salt intake and increase potassium intake. Because Prednisone causes sodium and fluid retention you may experience bloating and weight gain. Avoid highly salted foods. Add flavor with fresh herbs, low-salt spices, or a salt substitute. Prednisone also decreases potassium retention. Add foods high in potassium to your diet, such as bananas, citrus fruits, melons, and tomatoes.

Stomach Problems. Prednisone, especially taken over a long time, can cause irritation of the upper digestive system. Generally, over-the-counter antacids will help.

Skin Problems. Some people experience steroid induced acne on the face. Keep the skin as clean as possible, and discuss using an acne medication with your doctor. Other skin problems include slow wound healing, stretch marks, and redness of the face. It is important if you are on Prednisone to keep your skin clean and protected, and avoid skin trauma, including sunburn.

Eye Changes. Long term use of Prednisone can cause cataracts and glaucoma. Fortunately, the cataracts usually do not affect your vision. But if you have glaucoma, you need to continue your treatment for glaucoma. Prednisone is a potential risk factor for glaucoma.

Osteoporosis. Osteoporosis is a decrease in bone density, or “thinning” of the bones. Osteoporosis, a major cause of fractures, is usually associated with older, post-menopausal women. But Prednisone may cause osteoporosis in people who are not usually at high risk, such as males and young people. Following are suggestions for reducing the risk of osteoporosis.

- Eat calcium-rich foods. Eat low fat dairy products and certain vegetables including kale, turnips, collard greens, and broccoli. Try to consume 1,500 mg of dietary calcium each day. If necessary take calcium supplements.
- Get enough vitamin D. Vitamin D is necessary for absorption of dietary calcium. The best way to get Vitamin D is by exposure of your skin to sunlight. If this is a problem, take a vitamin D supplement.

Weight bearing exercise. Weight-bearing exercises are important to help reduce bone loss.

- Buy a pair of weights and use them while watching TV to exercise your arms and legs. Join a gym and participate in a regular exercise program. Ask one of the trainers to show you some safe, weight-bearing exercises. You’ll not only lower the risk of osteoporosis, but you’ll also help fight the weight gain and muscle loss caused by Prednisone.

Consider medications to strengthen bones. Fosamax® (alendronate) has been shown to strengthen bones weakened by osteoporosis. Or, if you are a post-menopausal woman, consider taking hormone replacement therapy. Consult your doctor about these options.

Have a bone density scan. It’s simple, painless, and will let you know if you are developing osteoporosis. You may want such a scan, called a bone densitometry, when you start taking Prednisone in order to establish a baseline. Then, you can have regular scans to see if there are any changes.
many patients experience withdrawal symptoms as the dose is reduced. You may experience muscle soreness, joint pain, fatigue, and depression. These effects are also temporary and worth tolerating to allow a cutback in your dose.

If you experience any unusual symptoms as your Prednisone dose is reduced, contact your doctor. It may be necessary to temporarily increase your steroid dose until you are feeling better and then taper the dose more slowly.

Taking Prednisone properly. To minimize the side effects of Prednisone it must be taken properly.

- Unless instructed otherwise take Prednisone all at once with breakfast.
- Prednisone is best taken with food.
- Take the prescribed dose. Do not alter the dose yourself.
- Don’t skip doses. If you forget a dose, take the normal dose as soon as you remember, and resume your schedule the following morning. If you do not remember until the next day, skip the missed dose.
- Do not abruptly stop taking Prednisone. Stopping “cold turkey” can cause an acute withdrawal reaction. Prednisone must be slowly tapered under your doctor’s supervision. When you travel keep all your medications in your carry-on baggage to reduce the risk of loss.
- You may require an extra dose during physically stressful situations such as major surgery or severe infections. Be sure all your doctors know you are on chronic Prednisone therapy. Wear a MedicAlert® ID bracelet. (See page 8.)

For more information consult your physician. We also suggest you read the book Coping with Prednisone by Eugenia Zuckermand and Julie Ingelfinger, M.D. St. Martin’s Press, NY. 1997 ISBN 0-312-15502-6.

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**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 Acting Director 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.

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What Are Autoimmune Diseases?

As many of you know pemphigus/pemphigoid are autoimmune diseases.

The following Q&A provides information to help you better understand autoimmunity.

The word “auto” is the Greek word for self. The immune system is a complicated network of cells and cell components that normally work to defend the body and eliminate infections caused by bacteria, viruses, and other invading microbes.

If a person has an autoimmune disease, the immune system mistakenly attacks self, targeting the cells, tissues, and organs of a person’s own body. A collection of immune system cells and molecules at a target site is broadly referred to as inflammation. There are many different autoimmune diseases, and they can each affect the body in different ways. Pemphigus vulgaris, the most common of the pemphigus diseases, affect the skin and mucous membranes. In multiple sclerosis, the autoimmune reaction is directed against the brain. In Lupus, one person may have affected skin and joints whereas another may have affected skin, kidney, and lungs.

Ultimately, damage to certain tissues by the immune system may be

permanent.

How Does the Immune System Work? The immune system defends the body from attack by invaders recognized as foreign. It is an extraordinarily complex system that relies on a elaborate and dynamic communications network that exists among the many different kinds of immune system cells that patrol the body.

At the heart of the system is the ability to recognize and respond to substances called antigens and to determine whether they are infectious agents or part of the body (self antigens). Most immune system cells are white blood cells of which there are many types. An antibody binds to an antigen and marks the antigen for destruction by other immune system cells.

How Are Autoimmune Diseases Diagnosed? The diagnosis of an autoimmune disease is based on an individual’s symptoms, findings from a physical examination, and results from laboratory tests. Autoimmune disease can be difficult to diagnose, particularly early in the course of the disease. Symptoms of many autoimmune diseases—such as fatigue—are nonspecific.

In some cases, a specific diagnosis can be made. A diagnosis shortly after onset of a patient’s symptoms will allow for early aggressive medical therapy; and for some diseases, patients will respond completely to treatments if the reason for their symptoms is discovered early in the course of the disease.

Although autoimmune diseases are chronic, the course they take is unpredictable. A doctor cannot foresee what will happen to the patient based on how the disease starts. Patients should be monitored closely by their doctors so environmental factors or triggers that may worsen the disease can be discussed and avoided and new medical therapy can be started as soon as possible. Frequent visits to the doctor are important in order to the physician to manage complex treatment regimens and watch for medication side effects.

What causes autoimmunity? The immune system normally can distinguish “self” from “non-self.” Some lymphocytes are capable of reacting against self, resulting in an autoimmune reaction. Ordinarily these lymphocytes are suppressed. Autoimmunity occurs naturally in everyone to some degree; and in most people, it does not result in diseases. Autoimmune diseases occur when there is some interruption of the usual control process, allowing lymphocytes to avoid suppression, or when there is an alteration in some body tissue so that it is no longer recognized as “self” and is thus attacked. The exact mechanisms causing these changes are not completely understood.

Are autoimmune diseases inherited? The genes people inherit contribute to their susceptibility for developing an autoimmune disease. Certain Diseases can occur among several members of the same family. The ability to develop an autoimmune disease is determined by a dominant genetic trait that is very common (20 percent of the population). This suggests that

Continued next page
Continued from previous page:
a specific gene or set of
genes predisposes a fam-
ily member. The genetic
predisposition alone does
not cause the develop-
ment of autoimmune dis-
ease. It seems that other
factors need to be present
as well in order to initiate
the disease process. In ad-
dition, individual family
members with autoim-
une diseases may inherit
and share a set of abnor-
mal genes, although they
may develop different au-
toimmune diseases. For
example, one first cousin
may have lupus, another
pemphigus, another
Sjogren's syndrome. It is
important for families
with members who have
an autoimmune disease to
mention this fact when
another member of the
family is experiencing
medical problems that
appear to be difficult to
diagnose.

What are the types
of autoimmune? Parti-
cular autoimmune disor-
ders are frequently classi-
ified into organ-specific
disorders and non-organ-
specific types. Autoim-
mune processes can have
various results: for ex-
ample, slow destruction
of a specific type of cells
or tissue, stimulation of
an organ into excessive
growth, or interference in
its function.

Organs and tissues
frequently affected in-
clude the endocrine
glands, such as the thy-
roid, pancreas, and adre-
nal glands; components
of the blood, such as red
blood cells; and the con-
nective tissues, skin,
muscles, and joints.

Some autoimmune
diseases fall between
the two types. Patients may
experience several organ-
specific diseases at the
same time. There is, how-
ever, little overlap be-
tween the two ends of the
spectrum. In organ-spe-
cific disorders, the au-
toimmune process is di-
rected mostly against one
organ. Examples, with
the organ affected, include
Hashimoto's thyroiditis
(thyroid gland), perni-
cious anemia (stomach),
Addison's disease (adre-
nal glands), insulin-de-
pendent diabetes mellitus
(pancreas), and pemphi-
gus (skin).

In non-organ-specific
disorders, autoimmune
activity is widely spread
throughout the body. Ex-
amples include rheuma-
toid arthritis, systemic lu-
pus erythematosus (SLE
or lupus), and dermato-
myositis.

Are they Con-
tagious? No autoimmune
disease has ever been
shown to be contagious
or "catching." Autoim-
mune diseases do not
spread to other people
like infections. They are
not related to AIDS.
Source: AARDA, NIH.
The gathering was at the Sag Harbor restaurant in Manhattan. All members and guests shared in a wonderful time and some expressed the desire to make this an annual event.

Members meet for brunch in NY

By Matt Koenig

On Sunday, December 10, 25 members and spouses of the New York chapter got together at the Sag Harbor restaurant in midtown Manhattan to eat, talk and relax. Our brunch deal included one drink and a choice of fine food. We sat at a long table so the conversations got splintered and isolated, but there was never a loss for words in any section of the table.

This was a first time that we tried a different venue for our meeting, and it was very successful. There were no speakers, no experts, and no agenda. By scheduling our meeting for a weekend, many spouses and significant others were also able to attend. We all had a chance to "loosen up" and get better acquainted, especially after the Mimosas. With several new members in attendance, our old-hands had a chance to provide some group history, the latest happenings, and plenty of recommendations for getting a handle on pemphigus. Afterwards, members of the group dispersed to see a Sunday matinee, get in some last minute holiday shopping, or even put on a pair of sunglasses and pretend to be tourists.

Based on the group's reaction, we will try to have more of these types of meetings in the future.

Toronto schedules meeting

The next meeting of the Toronto support group is Wednesday, June 27 at 7:00 PM at the North Toronto Community Centre, Games Room, 200 Eglinton Avenue East.

HELP WANTED: ACE REPORTERS

Do you like to write? Do you enjoy research? We may have the perfect opportunity for you. The Foundation is seeking volunteer writers for The National Pemphigus Foundation Quarterly. Write about your personal experience with pemphigus, a new treatment you have learned about, or anything else you would like to share with others who are living with pemphigus.

Or, if you prefer, we'll select a topic for you to write on assignment. A regular column is also a possibility. Everyone is welcome. No experience necessary. Flexible hours.

A wonderful chance to enjoy the reward of helping others while satisfying your creative urge. Please contact Janet Segall, 510-527-4970 or pvnews@aol.com.
Something new at the American Academy of Dermatologists meeting

Every year we make our presence known at the Annual American Academy of Dermatology (AAD) Convention by setting up a table so that the participants (physicians and exhibitors) can stop by and get to know us. There are usually somewhere between 7,000 and 9,000 Academy members (doctors) attending these meetings.

We want the doctors to tell their patients there is a place for them to go for support. We want the drug companies to know that there are diseases out there called pemphigus and pemphigoid.

Most of the doctors that pass by our table do not stop but, as we become a fixture at this meeting, and our name is being seen every year, often a doctor will now stop by who wouldn’t have before and doesn’t have a pemphigus patient but will take a brochure to keep in the office just in case. This year, the Convention will be held at the Washington Convention Center, March 2-7, 2001.

In years past, we were not allowed to attend any of the lectures given by the doctors but this year, through the hard work of the Coalition of Patient Advocates for Skin Disease Research (CPA-SDR), we will be allowed to attend. Janet Segall will be attending two meetings this year - one on pemphigus, and one on side effects of corticosteroids. She will report on these lectures in the next issue of the newsletter.

We have several volunteers to help us man the table this year and we thank them for offering their time.

Foundation to make annual trip to Washington for NIAMS

As a part of the Coalition for Patient Advocacy for Skin Disease Research (CPA-SDR), we go to Washington D.C. and meet with Senators and Representatives to encourage them to continue to support research at the NIH.

This is the third year of a five-year program to double the NIH budget. We hope that the new Administration will also see how important it is to support research in these areas.

This year is the 15th anniversary of the National Institutes of Arthritis Musculoskeletal and Skin Diseases (NIAMS).

The NIAMS has a broad mandate. It leads the Federal effort on research into the basic understanding, causes, treatment and prevention of diseases of bone, joints, muscle, skin and other connective tissues.

The diseases and disorders represented by these associations are common, costly, chronic, and can be crippling.

At this upcoming NIAMS Day, for his work in Congress on research issues, NIAMS will be giving Senator Tom Harkin an award at the evening reception.

We will also be visiting the NIH and meeting with Dr. Steve Katz, Director of NIAMS and taking a tour of the skin research labs.
NPF Donors list for 2000

The National Pemphigus Foundation is deeply indebted to all those who contributed to our cause, the fight against pemphigus and pemphigoid. Because of your generosity, our fight will continue well into the future. Thank you.

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Vincent & Bice Scotti
Lynn Sevasti
Eileen Segall
Angelina and John Selvaggio
Lupe Helen Sharp
Karen K. Sheehan
Penelope Sherwood
Joseph Sillers
Mr. Robert Shoklin
Gerard Stankiewicz, M.D.
Kathy Steinmacher
Joel B. Slesman, M.D.
Annette Sowa
Raymond Spalos
Mary Jo Storoz
Dorothy E. Strayer
Elizabeth Suenderle
The Arroyo Family
Mrs. Angie Thomas
Jerry Thompson
Stephan M. Todd
Deborah Tolzer
Carrie Twachtman
Charles Valenti
Andrew van der Pol
Rene Van Meter
Kim D. Vos
Andrzej Wallace
Irving Weinstein
Anita Weiss
Gail H. Weitz
Rose D. White
Janene Wiatr
Marjorie Wilder
Irene Wilkinson
Alta R. Wilke
Warren Wilkins
Barbara Williams
Dorothy A. Williams
Mary L. Williams
Eike Wittenberg
Nancy Woolley
Carole Wright
Eholi K. Zeh

Also Noted
In memory of Betty L. Buck
In memory of Dorothy Mayer
In memory of Ethel Elizabeth McErlay
In memory of Robert Gabinet
Sandra & Herb Feldstein- A very happy
50th Anniversary
Join us in Anaheim this July!

It's that time of the year again where we begin to start preparations for our upcoming patient/doctor meeting. This will be our 4th Annual Meeting.

The last four meetings were great successes. This year, the meeting will be in Anaheim, California (piggybacking off the American Academy of Dermatology's Summer meeting). The meeting will be the weekend of July 28-29, 2001.

This will be a one-day meeting full of interesting speakers providing information to you on pemphigus, pemphigoid, and related health topics. In the evening, we will sponsor a dinner that will bring together the speakers and attendees to create a more personal atmosphere. At the dinner, you will be able to ask those extra few questions you had that were not answered at the meeting.

We not only encourage patients to attend but we invite family and/or caregivers as well. We would like some indication as to how many people think they will be able to attend. We have a few questions we'd like to ask. If you are interested, please write, call, fax, or e-mail the office.

Would you like to attend the 4th Annual Patient meeting? If so, how many people do you think would be joining you? Would you be interested in any outside activities such as a visit to the new park adjacent Disneyland, Disneyland, or other activities (we'd like your ideas).

We believe that these meetings are an important way for patients to connect with others living with pemphigus/pemphigoid and with the doctors who are the experts. Our past meetings have shown us the value of these conferences. We hope as many as possible will be able to come and join us in Anaheim.