Peptide-based Therapy for the Treatment of Pemphigus Vulgaris

by Kai Wucherpfennig, M.D., Ph.D, Assistant Professor, Dana-Farber Cancer Institute and Harvard Medical School.

Pemphigus vulgaris is caused by the misguided attack of the immune system against the skin. Such diseases are referred to as "autoimmune diseases". Particular genes that are important in initiating an immune response confer susceptibility to pemphigus vulgaris. These immune response genes encode proteins that present short fragments of proteins (peptides) to cells of the immune system.

The goal of our studies is to determine which protein fragments (peptides) are responsible for the immune system's attack against the skin in PV patients. These peptides will then be modified such that they do not stimulate but rather block the cells of the immune system involved in PV. Studies in several animal models of autoimmune diseases have demonstrated that such modified peptides are effective for the treatment of experimental autoimmune diseases. The major advantage of such a therapeutic approach is that it would be selective for the cells that do the damage and that it would not compromise the ability of the immune system to fight infections.

Basically, what Dr. Wucherpfennig has done is create a peptide that will mimic the pemphigus antigen and kill the cells of the immune system that induce the production of antibodies, without affecting those immune cells that fight bacteria and viruses.

As of Janet Lehne's meeting with him recently in Boston, Dr. Wucherpfennig has succeeded in producing this peptide and plans to initiate a clinical trial that will determine its efficacy. Dr. Wucherpfennig believes, theoretically, that the same method (using the appropriate peptide for the respective disease) may work in patients with other autoimmune diseases. A number of steps need to be taken before clinical testing can begin (funding, toxicity studies in animals, approval by institutional review boards, FDA approval).

The Foundation supports and applauds Dr. Wucherpfennig's research and looks forward to the PV peptide testing to start in the near future.
Due to the growing interest in The Pemphigus Foundation, we have decided that the time is right for the establishment of our Medical Advisory Board. We have invited the following physicians to join this Board, and are extremely pleased to let you all know that they have accepted. All of these physicians are dedicated to helping their patients, finding a better treatment and/or cure for pemphigus, and have pledged their continuing support for the Foundation.

Our Medical Advisory Board:

- Grant Anhalt, M.D.
  Head of Dermatoinmunology, Johns Hopkins Dermatology, Baltimore, Maryland, and the Foundation’s Vice President in Charge of Scientific Affairs

- Dr. Jean-Claude Bystryn, M.D., P.C.
  Department of Dermatology, New York University Medical Center, New York

- Joyce Rico, M.D.
  Associate Professor of Dermatology, Department of Dermatology
  NYU Medical Center, New York

- Victoria Werth, M.D.
  Department of Dermatology, University of Pennsylvania, Philadelphia, PA

- Masayuki Amagai, M.D., Ph.D
  Assistant Professor Department of Dermatology, Keio University School of Medicine Tokyo, Japan

- Sarah Brenner, M.D.
  Department of Dermatology, Sourasky Medical Center, Ichilov Hospital
  Tel-Aviv, Israel

We have received a memo from United Way that informed us that if you contribute to The National Pemphigus Foundation through the donor designation program, the suggested minimum donation is $24 due to the impact on administration costs. Their explanation is that these donations “require additional processing and follow-up administration in the form of tracking, agency reporting, and a year-long payment cycle. It is not cost effective to continue to provide this additional support for designations which can be as low as $5 or $10.”

Due to the overwhelming costs of printing the newsletter, and subsequently sending them out, we will have to remove those people who have not sent us a donation (even $1) for the newsletter, or have not shown any particular interest in continuing to receive one, from our mailing list. We wish we could afford to continue sending out free newsletters, but our financial picture, at this point, does not afford us that luxury. We realize that $25 or $35 American dollars are a lot of money for some of our friends here and overseas, so we will continue to send newsletters to those who cannot afford this, but please let us know that interest is still there.

Janet Lehne and Alice Hammel went to Davis, California to meet with physician and researcher Dr. Sergei Grando, M.D., Ph.D., D.Sci., Professor, Department of Dermatology, University of California. Dr. Grando is looking into the link between neuroscience and pemphigus, with very interesting results which we will report to you when he is ready to publish his work.

Arlene Stauss-Popper in Lincolnshire, Illinois has the idea that we could sell t-shirts and bumper stickers with the sentiment - Support The National Pemphigus Foundation (See Arlene’s write-up in the Support Group Section). We discussed this, and believed that this might be a good way for us to advertise ourselves, to let people know we are here. It might be a way to get some recognition. We would like your opinion on this. Write, call, or e-mail Arlene or the Foundation as to what you think!

In February the annual meeting of the American Academy of Dermatology will be held in Orlando, Florida, February 27 - March 4, 1998. The Foundation would like to be able to send two people there to work the Convention. One of the most important ways we have to attract the attention of physicians is for us to be there! Let us try and make sure we get people to this important event. Please send us all your fund-raising ideas!!

Representative Ron Dellums, pictured here with our own Janet Lehne, has made a commitment to doubling the funding to the NIH over the next five years.
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Gregory Davis  
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(Leader, NY Support Group)  

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(Has had pemphigus vulgaris for 30 years)  

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It is the policy of the Pemphigus Foundation to keep the names and addresses of our members confidential. However, some have expressed an interest in networking and making their names public. If you would like to be on this list, please contact the Foundation.
I just recently returned from trips to Los Angeles, New York, and Boston. I am very encouraged by the enthusiasm and dedication of the researchers, physicians, and people living with pemphigus whom I met during the several trips I have taken in the last few months. I am optimistic that in the near future, we will have a better treatment for pemphigus and that we will be able to have meetings just because of the friendships we have forged and not because we share a bond of disease.

Unfortunately, reality dictates that in order to continue the Foundation’s operations, we need to have a better financial outlook. The running of the Foundation has grown and it is becoming increasingly more difficult for me to perform all the duties involved alone especially in the space that I now have designated as the “office”.

There are several wonderful people helping me in trying to raise funds to keep us going, but it almost seems like an impossible chore. We are a nonprofit organization, so I’m asking everyone who can use a tax write-off for their company to think about using a donation to the Foundation, and for those who work for others, mentioning us your employer to use in this way.

I am animated by the wonderful, caring people I have met on my travels, and I look forward to meeting more people with pemphigus, more researchers, and more physicians involved with treating pemphigus. I hope that the future will afford me the opportunity to do so.

We realize that there are some readers who feel that including a dedication to those who have died from pemphigus or complications of pemphigus treatment, or by including writing of those individuals may make some of you uncomfortable.

Those people who “fought the good fight” and lost deserve our attention, caring, and recognition. We need to let their families know that we feel this way in a public manner. I believe that, regardless of pemphigus, we can soar. Hearing about people who have lost their battle with pemphigus can make us stronger and more willing to do what we can to live our lives more productively. We all need to find our own place in the world, in our own time, and at our own pace.

IN MEMORIUM

We would like to send our condolences to the Uhrir family in Lake Placid, New York. Helene Uhrir, who had pemphigus, died from unrelated causes. I had recently spoke to Helene and she seemed well, but apparently she had undetected cancer which spread rapidly. I heard the news about Helene because her son sent me a letter informing us that Helene had put us in her will. On behalf of the Foundation, I want to thank Helene and her family for her generosity.

Pemphigus Foundation

Executive Director:
Janet Lehne

Newsletter Editor:
Steve Shapiro

The Pemphigus Foundation is a non-profit 501 (c)3 organization committed to education, outreach and research on behalf of people living with pemphigus and their families.

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On-Line Support Group
by Miriam Schneidmill

Thanks to the work of a bunch of computer enthusiasts, we are online with online support. We have started a Listserv called pemphigus_support@cyberwar.com.

This is a mailing list designed to make it easier for us to remember who is on the list. The list remembers. So you write your message to the list and everyone on it gets a copy. Then, if anyone wants to respond they can respond either to the list, or to the individual who posted the message.

To get started, you need an email address. Then send a message to majordomo@lists.cyberwar.com. In the body of the message put subscribe pemphigus_support. Pretty simple. If I don’t know you, I will drop you a line to get some introductory information and then you will be on the list. The list will send you instructions about how to remove yourself should you want to do that.

I can be reached at zapot@cyberwar.com and I look forward to seeing you online.

New York Support Group
by Joan Delucie

The May meeting of the New York Chapter Support Group was very successful. There were more than 30 patients and notable supporters who attended the meeting at New York University Medical Center. Our guest speaker was the esteemed Jean-Claude Bystryn, M.D., P.C., Professor of Dermatology at New York University Medical Center. Dr. Bystryn gave a brief profile on the challenging disease pemphigus vulgaris accompanied by an educational slide presentation. As a special request to several group members, Dr. Bystryn turned the remaining hour over for questions and answers. The time flew by as he graciously answered our questions attired in a tuxedo for his evening speaking engagement.

Also joining us that evening was M. Joyce Rico, M.D. Dr. Rico is the Project Director in a research study that is being conducted at NYU medical Center and Bellevue Hospital Center. The purpose of the research study is to determine if Dapsone is an effective steroid-sparing agent in pemphigus vulgaris patients unable to complete glucocorticoid tapering. Dr. Rico distributed consent forms for those interested in participating in the research.

We concluded our meeting with an open discussion by special guest Janet Lehne, President of the National Pemphigus Foundation. Ms. Lehne spoke about her trip to Washington and the main focus of the Foundation. Members of the group acknowledge their gratitude for having the opportunity to personally meet with and talk to Janet. They thanked her for establishing the Foundation and encouraged her to continue her good work and recognized what a difficult job she has undertaken.

In closing, Janet demonstrated the sentiments of the group when she thanked Dr. Bystryn and Dr. Rico for their participation and valued support. It was at this time that Janet announced that both physicians have accepted an invitation to serve on the Foundation’s Medical Board.

The next support group meeting has a tentative schedule for Thursday, September 4, 1997 at New York University Medical Center. An announcement to confirm the meeting will go out in August. Anyone wishing to contact me via E-mail, please send your correspondence to me at: jdelucie@aol.com. I look forward to hearing from you. Have a wonderful summer.

Philadelphia Support Group
by Miriam Schneidmill

The May meeting of the Philadelphia Support Group had a special twist. Michele Bernstein, Certified Journal Instructor, was kind enough to provide us with a journal workshop. Michele teaches Journal Writing at a number of sites in New York and New Jersey. We started with a “fill in the blank” exercise. Finish the sentence “I am happiest when...”. Those who cared to read their answers to the group and some discussion followed each exercise.

Continued on next page
I believe we walked away knowing a lot more about how to write away our worries and having learned the benefits of keeping a journal when you are ill.

As the second feature of our double bill, Dr. Werth had intended to present slides about the progress of the Dapsone study. However, she was tied up with patients and so our guardian angel, Barbara Sipe, RN showed the slides to those who were interested and Dr. Werth joined the group briefly to answer questions. The slide show will be rescheduled for an upcoming meeting for those who missed it. Hope to see you all soon.

Los Angeles Support Group
by Marcia Kassan

The L.A. support group of the National Pemphigus Foundation held its first meeting May 10, 1997. We were pleased to have Janet Lehne, the President/Executive Director, at our first meeting.

Our first speaker was Dr. Arnold Gurevitch from USC Medical Center and we learned so much from him! There were 13 of us at this meeting and in this short time we have really bonded together to support each other.

Our next meeting will be held July 27th at North Hollywood’s Medical Center. Lunch will be provided for a $5 fee. The guest speaker will be Kathleen Behr, Department of Dermatology, UCLA Medical Center. We are looking forward to having more people from the Southern California area, so that we can proceed with fund-raising ideas for research, so that maybe we can someday find a cure for pemphigus and other life-threatening skin diseases. Let’s support one another by showing up and reaching out to each other.

Contact Marcia Kassan for location and time at enterprise@loop.com or call her at home, (818) 340-7180.

Midwest Chapter Support Network
by Arlene Strauss-Popper

My daughter, Dana Silverman, is 21 years old and is living with pemphigus vulgaris (PV). We live in Lincolnshire, IL, which is a far north suburb of Chicago. Dana was diagnosed with this disease a year and a half ago. I saw the agony my daughter went through dealing with PV. After contacting Janet Lehne, I realized the efforts that she has put into the Foundation to keep it afloat. I also realized the need to contribute, the best I know how, and to lend a helping hand. It became apparent that more help was needed to accomplish the Foundation’s goals.

That’s when I decided to create the Midwest Chapter. Our goal at this time is to raise funds so that the Foundation will have the ability to create awareness of pemphigus, and to continue the efforts Janet has put into the Newsletter, and all the support she has donated to bring this community together.

The Midwest Chapter just ended it’s first fundraiser. We had a raffle. We exceeded our goal (which was $1,000.00), and I am proud to say that we brought in $1,255.00! There are still some donations coming in from people who did not want to participate in the raffle, but wanted to donate to our worthy cause.

As important as this first step was we have only scratched the surface. We need to continue in our efforts to raise funds. The Midwest Chapter had many people who put their efforts in selling the raffle tickets.

It gives me great pleasure to mention their names, and a great big

"THANK YOU"

for helping to make our goals reality.

Continued on next page
Without everyone’s help this raffle would not have been successful. I am very proud of everyone’s efforts. This is only the first step, but a very important one at that.

We are now in the process of doing our Summer Fund-raiser. This will consist of fund-raising by mail. Our hope one day, is to develop programs in the country from research to our advocacy efforts in Congress.

In the Fall we are looking into the possibility of selling Entertainment books. Anyone, or any group, interested in doing this, please contact me.

We would like to see that our chapter network stretches from coast to coast. We are in need of volunteers to accomplish this goal. If you are able to give a helping hand to those who live with this disease, we are reaching out to you for help. Let’s try to make a life-changing, lifesaving difference for anyone living with any form of pemphigus. It’s unfortunate, but true, generally only a handful of research projects are federally funded. One of our goals is to help to contribute to fund research of this disease. We cannot depend on federal funding, so we must continue on to help ourselves. If everyone can contribute in some way, whether it be financially, or helping us to raise funds to stop this chronic and sometimes fatal disease, it would bring us much closer to our ultimate goal... “It’s Just Beyond The Rainbow, Our Pot of Gold “A CURE”!

As part of our awareness program the Foundation will be offering t-shirts and bumper stickers for anyone who is interested. This is a terrific way of obtaining public awareness of the disease and the Foundation. All proceeds will go to the Foundation. The front of the t-shirt will have a rainbow on the upper left hand side, and wording on the back. Adult sizes - small to XX Large, specify children’s size.

The bumper sticker will bear the same wording and have a rainbow on it. Cost for the t-shirts and bumper stickers will include shipping: T-shirts - $15.00 each, Bumper Stickers - $2.50 ea. If you are interested in either of these items, either contact me:

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The National Pemphigus Foundation
Midwest Chapter
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San Francisco Bay Area
Support Group
by Janet Lehne

The SF Bay Area Support Group held its second meeting May 5, 1997. The group speaker, Ms. Clara Felix, a local licensed nutritionist, emphasized the importance of diet in controlling drug side effects, and the importance of keeping the immune system balanced, and in good working conditions. Ms. Felix is a strong supporter in Omega 3 fatty acids as a way to help our bodies recover. Omega 3 fatty acids are found in oils such as flaxseed. She has coauthored two books on the subject and was very informative and interesting. We would like to see more Bay Area people become involved with our group. If you are interested in attending a meeting, contact Janet Lehne at the Foundation’s headquarters.
As usual, it's been another exciting three months as I continue to educate myself about pemphigus and my body. As my pemphigus is currently active, I am taking Prednisone. Prednisone has many side effects, and ameliorating those side effects has become an important part of my educational effort. In this column we'll discuss some of the common side effects, and possible natural treatments for them. You are encouraged to educate yourself about these issues and make your own informed decisions.

A side effect can be defined as being an illness induced by a drug. In the case of pemphigus, we take drugs to suppress our immune system, but these drugs affect other parts of our bodies, causing them to malfunction. Pemphigus, in fact, can be caused as a side effect of the drugs d-penicillamine and captopril.

Some of the common side effects of Prednisone are: weight gain, Cushingoid syndrome (pumpkin face), osteoporosis, mood swings, sleeplessness, protein conversion, potassium depletion, frequent urination, gastric distress, diabetic manifestations and muscle tissue loss. Not everybody will have the same side effects, and side effects may be dose dependent.

Luckily, the natural techniques for ameliorating a few of side effects will address many of them.

To offset the mineral depletion, it is prudent to supplement both calcium and potassium in chelated form. Chelated minerals are bound with proteins, in a form that your body is used to seeing. Along with these, one should also take magnesium and a Vitamin D supplement to enhance the absorption and metabolism of these minerals.

There are a few things which should be removed from the diet of the person taking Prednisone that an otherwise healthy person may be able to tolerate. These items are: sugar (all forms), artificial additives, dairy, caffeine, refined carbohydrates, hydrogenated fats and all fried foods.

Aside from causing tooth decay, sugar (white sugar, brown sugar, honey, maple syrup, fructose, barley malt, maltodextrin, rice syrup, corn syrup, etc.) depletes minerals and vitamins, elevates cholesterol and blood pressure, causes hyperactivity, irritability, interferes with white cell function, weakens muscles, contributes to fatigue, and stresses the pancreas and adrenal glands.

Artificial chemicals, such as sweeteners and preservatives may be carcinogenic and cause allergic reactions.

Dairy proteins and sugars overstimulate the immune system, causing production of excess mucus. They also interfere with pancreatic function.

Caffeine stresses the adrenal glands, causes severe potassium depletion, interferes with mineral absorption, weakens muscles, causes nervousness, tremors, and loss of sleep.

Refined carbohydrates, such as white flour and white rice deplete minerals by requiring them to be pulled from your bones and tissues to enable their digestion.

Among other effects, hydrogenated fats and fried foods are sources of free radicals and interfere with metabolic and hormonal reactions.

All of these items should be removed from the diet of a person seeking to help themselves recover from a severe illness. Prove it to yourself. You probably have good days and bad days, and are never able to predict which will occur. For a period of one week, abstain from all fried foods. Note how you feel every day. On day 8, eat a generous portion of a fried food, such as potato chips. Note how you feel the next day. If you don't believe your lousy feeling was induced by the fried food, try it again and see if the same thing happens. You can try the same things with sugar and dairy, but you'll have to abstain at least 3 weeks before challenging them. These substances take longer for your body to clear. Caffeine is a highly addictive substance, and unless it is gradually withdrawn, will produce withdrawal symptoms such as headaches.

What should you eat? To offset the proteins that are converted to carbohydrates, a high quality source of protein should be eaten daily. Beans, nuts, seeds, and small portions of meat can meet this requirement, as can supplemental protein beverages. Eating a filling quantity of a variety of fresh (preferably organic) vegetables, grains, nuts and seeds everyday will provide the nutrients your body needs. Additional supplementation with Essential Fatty Acids, vitamins and minerals, and digestive enzymes should be considered.

For further reading, I suggest "Lick the Sugar Habit" by Nancy Appleton and "The Whole Way to Natural Detoxification" by Jacqueline Krohn MD.

This article represents Steve's personal experience and research. The information given is not medical advice nor is it presented as a personalized course of treatment.
Answers & Questions

The following information given is not medical advice nor is it presented as a personalized course of treatment. Please consider consulting with a physician or knowledgeable, licensed practitioner before trying any therapies.

How can I start a support group where I live?

We suggest that you begin by calling the main hospital’s and/or University hospital’s Dermatology Department in your area and inquire if they treat people with pemphigus. If they do, the Foundation can print up brochures with your name and address on them which you can distribute to the places that do treat pemphigus. If the Foundation database has the names of people in your area, we can send a letter informing those people to contact you in order to set up a group. When you have gathered a reasonable number of people and would care to have speakers, either you can ask your physician to speak at your meeting, or if the Foundation knows of a physician interested in pemphigus in your area, can write a letter on behalf of your group. Hopefully, at some time in the future, a representative of the Foundation will be able to join you at a meeting.

Which toothpastes are best for ulcerated mouths?

Check with your health food store for non-abrasive toothpastes. The tartar control toothpastes are not recommended for gums that are ulcerated. Baking soda or baking soda toothpastes can be used.

I am looking for the book “Heal me or Kill me!” mentioned in the last newsletter. Do you know where I can find it?

Milo Careaga found that the book can be purchased directly from the author. Write to: Mrs. Sandra Range, 7214 Society Dr., Claymont, DE 19703-1770 or call (302) 792-2935. The cost of the book is $10.00 + $1.50 for shipping and handling.

Do you have any information on Echinacea, Goldenseal & Cat’s Claw?

As researched by Steve Shapiro, Echinacea and Golden Seal are immune enhancers, and generally should be avoided by people with autoimmune illness. The exception appears to be in applying Golden Seal to blisters. Pemphigus blisters are infected with bacteria, viruses, fungus and parasites. Golden Seal is effective against these. It will not help to heal the blisters, nor will it decrease the autoimmune reaction.

Use of Cat’s Claw is speculative. There have been several people with Crohn’s Disease (also an inflammatory autoimmune condition) that may have benefited from taking Cat’s Claw. A minimum trial period to determine whether it will be effective is 3 months. Note that these people also changed their diets significantly and were involved in several other healing modalities. Although none are ‘cured’ they are able to live with their illness much better.

Where is the best place to find information on healthy foods?

Most health food stores have a book section that will have more up to date information than a library, they may even have chairs where you can sit and read. The internet has hundreds of sites providing herbal information, but be wary of the source, as many of them are multi-level marketing schemes. Steve’s internet site has several links to herbal and other reference sites.

What is your recommendation as to what foods to take with our daily morning dose of prednisone?

Many of readers wonder what foods to eat when taking their morning medication. The only reaction we have had is from some readers who suggest that they didn’t do as well if they ate cold bran cereals with their prednisone. Oatmeal seems to be fine as are bananas.
Survey

To help us all better understand pemphigus, please take a few moments to complete this survey. The results will be published in the next newsletter.

Gender: ○ male ○ Female
Age at diagnosis: ____________________________
Current age: ________________________________
Blood type: A B AB O + -
Type of pemphigus
○ Vulgaris ○ Foleacious
○ Vegetans ○ Pemphigoid
○ Other
Other diagnosed chronic illnesses:
1 ____________________________
2 ____________________________
3 ____________________________
Lesions are in:
○ mouth only ○ body only
○ mouth and body
Other symptoms/experiences
_____________________________________
_____________________________________
_____________________________________
Initial drug(s) & dosage:
○ Prednisone: ____________________________
○ Immuran: ______________________________
○ Other _________________________________
How did you respond to the drug?
_____________________________________
_____________________________________
_____________________________________
Looking back, can you discern any sign that you were becoming ill prior to the appearance of pemphigus? ○ yes ○ no
How many cavities have you had? ___________
Where? (if you know) _______________________
Describe your drug usage history:
_____________________________________
_____________________________________
_____________________________________
Current drugs and dosages:
1 ____________________________ 4
2 ____________________________ 5
3 ____________________________ 6
Side effects you have experienced:
○ osteoporosis ○ weight gain
○ potassium loss ○ ulcer
○ muscle loss ○ fatigue
○ emotional distress ○ Cushingoid
○ sleeplessness ○ Diabetes
○ others:
Vitamins & supplements you take:
_____________________________________
_____________________________________
_____________________________________
Herbs and other non-traditional therapies:
_____________________________________
_____________________________________
_____________________________________
Comments:
_____________________________________
_____________________________________
_____________________________________
In your opinion, prior to pemphigus, your health was:
○ Perfect ○ Excellent
○ Good ○ Fair
○ Poor ○ Lousy
Please return the survey to:
Steve Shapiro, PO Box 50335, Eugene, OR 97405-0977
If you have any questions about the survey, please call me at (541) 607-6037, evenings, 6-9pm Pacific Time.
If the phone rings more than 3 times, I am not there, and I will not return long distance calls.
A Look Toward Our Future

The Pemphigus Foundation is a 501(c)3 charitable organization. Our goals and objectives:

1) To increase awareness of pemphigus both among the general public and the medical community.
2) To provide emotional and informational support to both people living with pemphigus, their families, and friends.
3) To provide referrals to specialists and,
4) To support researchers looking for better treatments and a cure for pemphigus.

We are working very hard to see that the Foundation succeeds. We are asking for your help in making sure that we can continue to bring you all the news on pemphigus and its related subjects.

If you belong to a Service or Fraternal Organization (or other) group which provides financial contributions to charitable organizations, please suggest to them the National Pemphigus Foundation as a possible recipient. Please check with your employer or employers of others who make donations on your behalf to see if they have a gift matching program or accept grant proposals. This could provide essential support in our efforts to promote our goals and objectives.

We are open to ideas and suggestions as to what we should include in future newsletters. Please contact us with any thoughts on this matter. We are also grateful for articles you are willing to contribute.

Janet S. Lehne
President/Executive Director
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