Bullous Disease - Treatment

Grant J. Anhalt, M.D., Johns Hopkins University Baltimore, Maryland

Bullous Pemphigoid

Bullous pemphigoid is an acquired blistering disease. It is characterized histologically by subepidermal bullae and immunopathologically by in vivo deposition of autoantibodies and complement components along the epidermal basement membrane zone. Approximately one-half of these patients also have circulating autoantibodies directed against the basement membranes of stratified squamous epithelium. Because of these characteristics, bullous pemphigoid is believed to be an autoimmune disease in which the cutaneous lesions may result as a consequence of these anti-basement membrane zone antibodies. Generalized bullous pemphigoid required systemic therapy, using agents similar to those effective in PV but in lower doses and for shorter periods of time. Patients with localized bullous pemphigoid have responded well to therapy with topical or intralesional steroids alone (such as triamcinolone suspension). Systemic corticosteroids are the mainstay of therapy in generalized bullous pemphigoid; the most widely used preparation is prednisone.

Some individuals prefer a non generic brand of prednisone to ensure reliable absorption; others rely on intramuscular triamcinolone (Kenalog), 40 to 60 mg monthly, if compliance is a problem. Most series show that the majority of patients with generalized disease were controlled with 40 to 80 mg daily of prednisone, and only rarely was it necessary to exceed 80 mg daily. The severity of disease, age of the patient, and presence of underlying diseases, especially diabetes mellitus, tuberculosis, and hypertension, must be considered in determining the dose of corticosteroids.

Mild disease, which has been arbitrarily defined as presence of 20 lesions or less, usually responds to lower doses of prednisone (less than 0.5 mg per kg per day) than does moderate (20 to 40 lesions) or severe disease (greater than 60 lesions). Healing of existing lesions and cessation of new blister formation reflects a response to therapy. Once the disease is under control, the prednisone dose should be tapered slowly and eventually changed to an every-other -day regimen to minimize steroid side effects. A minority of patients may not respond to corticosteroids, or they may require a high maintenance dose of the drugs. These patients may benefit from the addition of an immunosuppressive agent. The most frequently used agents are azathioprine and cyclophosphamide. My personal preference is to use azathioprine as the first immunosuppressive agent in bullous pemphigoid. It is easy to administer; does not produce significant leukopenia and, therefore, does not require as close observation as other agents; and is generally well tolerated. In addition, it has some anti-inflammatory effects that are useful in bullous pemphigoid and are not found with other immunosuppressive drugs. Azathioprine is effective at doses of 1 to 2 mg per kg per day in bullous pemphigoid. Experience with cyclophosphamide in bullous pemphigoid is more limited, but it has also been shown to have steroid-sparing effects. It is

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

We believe we have been working hard toward these goals and have begun to make a dent with our first three objectives. Our support for researchers will come with better funding.

We would like to have a permanent page in the Newsletter with the names of people who are willing to be part of a support network. All those people who would like to have their names and phone numbers published are invited to inform Janet Lehne by e-mail, postcard, letter, etc. We do not want to invade anyone’s privacy by printing names without written permission. I want to thank all those people already making contact with others.

The National Pemphigus Vulgaris Foundation has joined the Coalition for Skin Disease Research. This group goes to Dermatological and Immunological conferences and provides the attendees with information about all of the member organizations.

In August the group attended a conference jointly sponsored by the American Dermatological Association and the Association of Allergy and Immunology. Miriam Schneidermill assisted by staffing the information table on behalf of the Foundation. She spoke to as many doctors as she could, telling them of our organization and giving them pamphlets to give to their new and current patients.

On March 11th & 12th, the representatives of each member organization of the Coalition will join together in Washington, D.C. to educate Congress on the need for more serious funding for skin disease research. Janet Lehne will be representing the Foundation at this event.

At the end of March, the American Academy of Dermatologists will be in San Francisco and Janet will also be hosting an information table at this event. We will need volunteers to help staff the table. We are hoping to meet with many physicians to enhance their knowledge of PV.

Don’t forget that if you are giving during the United Way Fund Drive, you may designate the Foundation as a recipient and we will receive a portion of those funds donated.

The Foundation is on the lookout for a table top copy machine. If anyone has one in their office or home they want to replace, we would love to take the old one off your hands. A small used one will run about $500, a new one around $700. We welcome any donations designated toward the purchase of a new or used copy machine.

**HONOR ROLL**

The National Pemphigus Vulgaris Foundation is grateful to its corporate and individual supporters for their generosity. Thanks to their support, the Foundation is able to continue its invaluable work. We extend our deepest thanks to all contributors, and those in particular who contribute toward the newsletter and tapes.

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These contributions reflect gifts received between January 1 and December 31, 1996.
Dapsone Study Off and Running

At this writing, FDA approval has been received for the multi-center Dapsone study.

Dr. Werth and the others in the study are attempting to discover whether or not Dapsone is useful as an adjuvant drug in the treatment of Pemphigus Vulgaris. They will be adding Dapsone to existing treatment for those patients who are unable to reduce their prednisone dosages below 15mg every day or 20mg every other day. If you are currently under treatment for Pemphigus Vulgaris and you are taking prednisone either 15mg every day, or 20mg every other day, and have been unsuccessful reducing this dosage please go to the most convenient center below to apply for the study.

This study will be "double blind" so that neither you nor your physician will know whether you are taking Dapsone or the placebo (a harmless pill designed to look like Dapsone but do nothing). However, if after 3 months you do not improve, you will be switched from whichever drug you are on to the other one. That way, if you receive the placebo and are not improving, you will get the Dapsone, and if you are receiving Dapsone, but not responding to it, you will be taken off of it.

For more information, please contact a center below, or Dr. Werth.
- Hospital of the University of Pennsylvania, Philadelphia, PA, Dr. Victoria Werth
- New York University Hospital, New York City, NY Dr. Joyce Rico
- Southwestern, Dallas, Texas Dr. Amit Pandya
- University of Miami Miami, Florida R. Francisco Kerdal
- Northwestern, Chicago, IL Dr. Diana Chen
- Cooper Medical Center, Camden, NJ Dr. Warren Heymann
- Case Western, Cleveland, OH Dr. Neil Korman

President's Message
by Janet Lehne

Looking back over the last year, I find that we have been quietly making progress toward our goals and objectives. A very successful support group started in Philadelphia, and hopefully, this year there will be one in the New York, Los Angeles, and San Francisco Bay areas. We've made contacts with one another. We've gotten our name out over the Internet. We've joined the Coalition for Skin Disease Research. We've been able to attract the attention of many physicians interested in helping their patients deal with their disease.

A new year is now beginning and I have hope and optimism for progress in all the areas that need our attention. We expect to attract the attention of the public and the medical community to educate them so that people with early PV do not get inappropriate diagnoses.

We look forward to being more present on the Internet with the development of a Home Page and an Internet support system.

We look forward to playing a bigger role in supporting research that will give us better treatments and, one day, a cure.

I want to thank everyone for their kind words, and the strength, confidence and faith to believe that if we work together, we can achieve everything we strive for in finding better ways to live with, fight against and survive Pemphigus.

Pemphigus Vulgaris Foundation

Executive Director: Janet Lehne
Newsletter Editor: Anonymous

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

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diated for patients who have unusually aggressive
disease and have failed to respond to other agents.
Methotrexate (7.5 to 15 mg weekly) has also been
used in a limited number of patients with success
but is usually less effective than other
immunosuppressives. Dapsone or sulfapyridine may
be useful in management of patients in whom corti-
costeroids are contraindicated or not tolerated. In
my personal experience, only about 10% to 15% of
patients show a convincing response to sulfone
therapy. Corticosteroid pulse therapy, in which pa-
tients are given 1 gram of methylprednisolone intra-
venously for 3 consecutive days, can also be success-
ful in initial control of patients with severe bullous pemphigoid.
Plasmapheresis has also been used in treating patients with bullous
pemphigoid, but it has only tem-
porary beneficial effects. In fact,
there is some evidence that the
concomitant use of plasmapheresis may increase the
chance of death from infectious
complications, so it is generally
not used. Cyclosporine has
proved beneficial in the treat-
ment of some bullous pemphi-
goid patients, but its inherent nephrotoxicity and cost
render it an infrequently used drug. Finally, there
have been reports of the effectiveness of a combi-
nation of oral erythromycin or tetracycline (2 grams
per day) and niacinamide (1,500 to 2,500 mg per day)
in the treatment of bullous pemphigoid. Anecdotal
reports have confirmed this report, but I have gener-
ally found it to be ineffective. It could be attempted
in patients with limited disease who likely would
not tolerate oral steroids well, but its usefulness will
have to be determined by larger studies.

Cicatrical Pemphigoid

Cicatrical pemphigoid is predominantly a disease
of the elderly, with a peak incidence between 60 and
80 years of age. Lesions can arise on any mucosal
surface covered by stratified squamous epithelium,
including the nasopharynx and oropharynx (nose and
eyes), conjunctiva (eyes), esophagus, larynx, urethra,
and anal mucosa. Morbidity and mortality is due to
the scarring that recurrent lesions produce. The ma-
jor criteria distinguishing bullous pemphigoid from
cicatrical pemphigoid is the presence of scarring sec-
ondary to the blistering, and that in bullous pem-
phigoid, cornified epithelium is the primary tissue
involved, whereas in cicatrical pemphigoid, mucosal
epithelium is primarily affected. Clinically, lesions
present as smooth bordered erosions with distinct
margins. The gingivae are commonly involved, and
cicatrical pemphigoid is one cause of desquamative
gingivitis. The conjunctival epithelium is affected in
about two-thirds of cases of cicatrical pemphigoid,
and it is cause for considerable concern. In the con-
jectiva, erosions are rare, and signs of active disease
include a violaceous inflammatory infiltrate, super-
ficial fine fibrotic bands, shrinkage of the conjunctival fornices, and
entropion. Lesions of the laryngeal,
esophageal, and genital mucosae con-
sists of smooth-bordered erosions,
with eventual stricture formation.

Skin lesions occur in more than
20% of patients and are usually tran-
sient. When the lesions are present,
they consist of small intact blisters
or erosions, usually in the head and
neck area. The diagnosis is estab-
lished by three criteria: (1) scarring
blisters and/or erosions, as described;
(2) subepithelial blistering on histologic examination,
with an intact basal cell layer and variable inflamma-
tory infiltrate; and (3) direct immunofluorescence of
perilesional epithelium showing IgG and comple-
ment components along the basement membrane
zone. In mucosal cicatrical pemphigoid, the indirect
immunofluorescent for circulating antibodies is
highly unreliable and is negative in the majority of
cases. It is important to obtain positive direct immu-
nofluorescence results, even if it requires repeat bi-
opsies, because the clinical and histologic features can
be closely mimicked by erosive lichen planus, and a
syndrome indistinguishable from cicatrical pemphi-
goid also occurs in about 10% to 15% of patients with
linear IgA dermatosis and epidermolysis bullosa
acquisita. Treatment is dictated by the organs in-
volved and the anticipated morbidity.

This disease is not highly steroid responsive, and
it is progressive. Spontaneous remissions are rare. For
example, if only the oropharynx and nasopharynx

Dapsone or sulfapyridine may be useful in man-
management of pa-
tients in whom corticosteroids are contraindicated or not tolerated.

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are affected, anticipated morbidity is minimal, and treatment should be limited to topical steroids such as fluocinonide gel (Lidex), intralesional steroid injections with triamcinolone, 10 mg per ml, or occasional short bursts of oral corticosteroids. This approach provides palliation but does not halt progression of the disease. If only the gingivae are involved, topical therapy with occlusion can be delivered by application of a flexible dental tray (similar to the disposable molds used to deliver fluoride treatments to the teeth), in which a medium-potency topical steroid such as betamethasone valerate (Valisone) ointment is applied. This can be used twice or thrice daily to provide convenient topical therapy of the attached gingiva.

A different situation exists if the eyes, esophagus, or larynx are involved. In such cases, the anticipated morbidity includes blindness and asphyxiation, and aggressive systemic therapy is warranted. Systemic steroids alone will not adequately control progression; most other therapies only slow the progression. The treatment of choice is oral cyclophosphamide, given in a regimen that has been confirmed to be effective in double-blinded studies. Initial therapy requires combined use of prednisone, 1.0 mg per kg per day, with tapering discontinuation within 6 months. Cyclophosphamide is started at the same time but is maintained for a period of 18 to 24 months at a dose of 1 to 2 mg per kg per day (until the white blood count is depressed).

About three-quarters of the patients treated with this regimen tolerate the drug, and at the end of this period, most of these patients will have complete clinical remissions that will persist after all drugs are withdrawn. To date, this cyclophosphamide regimen is the only treatment that provides the potential for a cure of this disease. Chlorambucil (Leukeran), 4 to 6 mg per day, is used as an alternative agent if cyclophosphamide is not tolerated. Occasionally, patients respond to oral dapsone, in doses of 100 to 150 mg per day. Those that respond well do so quickly, but unfortunately in our experience, these patients are a minority. Azathioprine is an alternative for patients that cannot tolerate cyclophosphamide, and it has fewer acute toxicities. The use of cyclosporine is not recommended owing to the chronicity of the disease. It is important to recognize that treatment with any agent other than cyclophosphamide or chlorambucil may suppress symptoms, but scarring will progress and eventual morbidity or mortality will not be avoided.

WHAT'S NEXT
by Miriam Schneidmiller

The sum of the dollars paid in for medical payments or insurance must equal the sum paid out. But to order the former, system, dollars paid in to the large academic centers such as those participating in the study were paid out to provide release of physicians interested in the medicine. Physicians like those participating in this study must be paid for their time. They will be paid for their time. Either they will see more patients so that their salaries are covered, or they will see fewer patients because the very real contribution they make to medicine, outside of the examining room, is recognized by the patients, the facilities and by the third party payers.

Pre-HMO, it is agreed that the third party payers may have had to pay “too much”. But to whom? Sometimes to the doctors themselves. But sometimes to an academic center where the excess was used to provide the extra time to the researchers. If we “clean up” the third party payer system and pare it down to the essentials, and force everyone to take the lesser payment the payers are willing to pay, we get the same medical care, an administrator gets the excess, and no one does research anymore.

As patients with a rare disease, it is up to us to ask, and to even demand that funding for research be part of every third party payer’s mission. We cannot let them scrimp on the bone and have not even a bone left to throw to the dedicated academic physicians who are interested in curing everything from the cold to cancer. I believe our voices can and do count. We must petition our elected officials to demand medical dollars for research as well as for treatment.

If you need help finding out where to mail your letter, please contact me at 201-471-2278 and I will find it for you “on the net”.

We've got a new address
PO Box 9606
Berkeley, CA 94709-0606
LIVING WITH PEMPHIGUS
by Siri Lowe

Until six months ago, I always thought of myself as a healthy person. I'd had the average quota of minor problems, but serious ill health seemed something that happened to other people. Then, in September, 1995, I developed mystery mouth 'ulcers' that became rapidly worse and which no treatment helped. A month later I was diagnosed as having PV. Suddenly I'd moved into the unknown territory of a 'rare and serious disease of the immune system'. I hope I've come to reasonable terms with PV, in so far as one ever can, yet there are still times when I don't believe in it myself. Part of me is still waiting for Jeremy Beadle (a BBC comic, ed.) to appear and say that it's all been a bad joke and it's over now.

Unremitting Lesion Pain: I think the hardest thing to come to terms with is the sheer scale of PV and its effects. I'm one of the lucky ones; so far, I have lesions only in my mouth, tongue, throat and nose. Even so, the effects have been extreme. The drugs and the disease together brought constant exhaustion, unremitting 24-hour lesion pain, nausea and inability to eat anything except liquids (yes, this diet certainly works). After some time on immunosuppressants alone, the situation has deteriorated and I've had to start taking high dose steroids (with their own consequent complex side-effects). My body can no longer fight other infections effectively and I have many other, more trivial health troubles. My life has changed completely. I'm too ill to work, I've had to stop the voluntary work I used to do and I've learned the hard way not to go out in the evenings - my exhaustion point is reached by 5pm, or 7pm if I'm lucky. There are end less hours of medical appointments - not less than one hospital visit a week and, often two or more.

Misleading Appearance: One of the strange aspects of PV is that it's not necessarily noticeable. In some ways that's a huge comfort, as I can try to lead a 'normal life' and no-one need know I'm ill. Not to appear disabled makes life 100% easier, as I found out when lesions affected my larynx and I was temporarily unable to speak. It's frightening how unhelpful and hostile some people are if you're disabled, including some hospital and health centre staff.

There is however, a downside to not appearing ill. It is often forgotten how awful you feel with PV. It isn't just the painful lesions - they are, after all, only the presenting symptom - it's also that your immune system has malfunctioned and you feel absolutely lousy, often in subtle ways. I can have a whole day when I feel fine, but it's rare.

Limited Time to Care: I'm still surprised that most of my doctors haven't wanted to find out about how PV feels on the inside. After all, it's a rare disease and I would have thought the information would be useful. True, it would be my subjective opinion and any conclusions would be hypothetical, but most information starts as subjective until it's collated, tested and becomes the standard opinion. However, I dare say nobody asks because there is only time in the NHS to cover the essentials. That, for me, is where some major problems lie. Most doctors have been marvellous, although one GP told me to go away, "you only have a sore mouth". I've been enormously lucky with my hospital specialist (and his team) who is kind and supportive and takes into account my opinion of what I think is happening with the disease - an attitude that I value. My GP has done all he can to look after my weakened general health. However, he knows little about PV and the hospital staff (understandably) only has time to deal with lesions and drug maintenance. Therefore, each doctor thinks I should see the other about my problems. It's like being on the spokes of a wheel with everyone pulling you on to the next spoke. It seems that the NHS simply is not structured to allow for rare diseases that fluctuate and take up time. One practice manager even told me to take up less appointment time and, as I don't want to be struck off, I see my GP only when emergencies arise. Not exactly sensible preventive medicine! Without drugs and medical help I would be moving towards an inevitable and unpleasant death, so I'm truly grateful for the help I received. Yet I'm convinced there are ways that the NHS could better help PV sufferers.

Solid Information Needed: From the start, I've wanted as much information on the disease as possible. My view is, the more I know, the more sensibly I can deal with problems that arise. Yet I've found it impossible to get solid information from doctors.

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Everyone seems convinced that it’s bad for patients to know about a “depressing” illness. What does make me feel awful is being kept in the dark and so being unprepared. I spend many hours in hospital waiting rooms, listen to other patients and I know I am not the only one who feels this. Certainly, some patients do not want to know about their illness. Many, however, do and, like me, they do not appreciate doctors refusing to help them find out. It is similar with support groups. I wanted to find one, not to ‘wallow in the disease’ but for straightforward answers to questions like: “Is it normal to taste metal in your mouth all the time?” “Is it normal to spit out streams of blood after epithelial tags?” Since PV is a rare disease, doctors may not know the answers, but other PV patients might. I believe doctors would ultimately have to spend less time with PV patients if they helped us to get the information we ask for. PV is a cruel disease. I wish that this was all happening to someone else. I remain fascinated, however, by the puzzle of what happens when the autoimmune system goes wrong. Despite the hard times now, I believe a combination of drug therapy and complimentary medicine (which I also take) will be able to control the disease and give me a good chance of remission with a reasonable quality of life.

(Siri is a resident of the United Kingdom. This article appeared in the July/August 1996; Dermatology in Practice)

## Spiritual Aspect of Healing

by Steve Shapiro

When I first started my healing journey, I knew that spiritual healing would be part of it. Being a somewhat atheistic person of Jewish descent, I didn’t have a single clue as to how to start on that journey. I volunteered to write a three-part article on healing for the PV newsletter, the third one of which (this one) is to deal with the subject of spiritual healing. Now I was really in a quandary. How was I, an atheistic atheist, going to write an article about spiritual healing for such a diverse group of people? People Living with Pemphigus come from all races, cultures and religions. The only thing we appear to have in common is a malfunctioning immune system.

That was five months ago. I’ve learned a lot in those five months about myself and what the term “spiritual healing” means to me. As with most of my research, what I’ve learned has left me with more questions than answers. Each time I find an ‘answer,’ it always leads to two or more new questions. In fact, one clinical study I read came to the conclusion that there are no answers!

In the Western world we measure God’s presence in our lives by our level of personal comfort, we believe God is here if our prayers are answered. But neither the Judeo-Christian God nor Buddha nor any other spiritual leader or tradition guarantees or encourages a pain-free life. Spiritual teachings encourage us to grow through and past painful experiences, each of which is a spiritual lesson.

The first thing to do is understand what the term spiritual healing means. What is the difference between spirituality and religion? Religion is a group experience. The root of the Latin term ‘lig’ means ‘to join together.’ Catholicism, Judaism, Muslim, etc. are examples of religions, people joining together. Spirituality, on the other hand, is the internal pro-

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**Heart to Heart**

It is the policy of the PV Foundation to keep the names and addresses of our members confidential. However, some of our members have expressed an interest in networking with each other, and making their names public. If you would like to be added to this list, please contact Janet at the Foundation.

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Spiritual Aspects

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cess with which a person meets their religion. What is happening inside me is my spirituality. If I express that in a group, then my religion is an expression of it. For those of us who were born into a faith, it is possible to be very religious, but not spiritual; that is, we have never had an internal experience of our belief.

One thing to consider is the term “spirit.” What is it, do I have one, and why is healing so important? Western thought presents the spirit or soul as something that leaves the body when we die and continues. That may or may not be so, but if it is, it leads to the following question: What does the spirit do while we are alive? Does it hang around and do nothing but wait for us to die, or does it interact in some way with our physical body? If the spirit becomes sick or injured, can it affect our physical bodies? Can physical stimuli affect the spirit? I am beginning to understand my answers to these questions.

My spirit, my energy and my personal power are all one in the same force, and yes, what happens in my life does affect my spirit. If my spirit is weakened, my physical body is also weakened. This is my answer, it is up to you to find your own answers.

The next thing to understand is the difference between healing and curing. A cure occurs when one has successfully controlled or abated the physical progression of an illness. Curing a physical illness, however, does not necessarily mean that the emotional and psychological stresses that were a part of the illness were also alleviated. The process of curing is passive. That is, the patient is inclined to give his or her authority over to the physician and prescribed treatment. The chemical and mechanical treatments of conventional medicine require little conscious participation by the patient.

Healing, on the other hand, is an active and internal process that includes investigating one’s attitudes, memories, and beliefs with the desire to release all energies that prevent one’s full physical, emotional and spiritual recovery. It requires and demands full participation by the patient in his or her own life and the decisions that affect it.

The most important questions which arise are: How did I become ill, and do I want to heal? Energy medicine is a holistic philosophy that teaches, “I am responsible for the creation of my health. I therefore participated, at some level, in the creation of this illness. I can participate in the healing of this illness, which means simultaneously healing my emotional, psychological, physical and spiritual being. I am not a victim.”

It would seem that the obvious answer to the second question, (Do I want to heal?) is yes. After pondering this one, I realized it wasn’t so simple. Becoming addicted to our illnesses and wounds is possible. As we cycle deeper into the powerlessness of illness, the more dependent we become on others. We may lose so much of our personal power that it becomes comfortable, and the thought of being healthy becomes scary. Healing requires taking action. It is not a passive event. We are meant to draw on our inner resources, to find the material strength to leave behind our outdated beliefs and behaviors, and to see ourselves in new healthy ways.


Steve Shapiro is a 38 year old man living with Pemphigus Vulgaris. He has developed a rational theory explaining how he developed PV. Based on this theory, he is constructing a personal treatment plan based on traditional and alternative therapies to heal his body. You are invited to contact him.

Supporting Yours

by Miriam Schenmdill

The November meeting of the Philadelphia Support Group was a great success. Our speaker was Dr. Barbara Wingate, a psychiatrist at the Hospital of the University of Pennsylvania. Her topics included the psychology of chronic disease, the spiritual needs of the patient, and the need for support for spouse or significant other of the patient.

Dr. Wingate’s tape is now also available for ordering. There are still Dr. Werth and Dr. Stanley tapes available. Send Janet a $10.00 donation for each tape that you would like. Dr. Werth spoke on the treatment of Pemphigus and Dr. Stanley spoke on the science of Pemphigus. Both talks were quite good. We are arranging a nutritionist for the January/February meeting in Pennsylvania and hope to have a Journal Writing workshop and a Reiki demonstration in the future. If these interest you, please let me know by mail, phone or e-mail. If you would like to start a group where you live, please call me and I will help in any way I can.

See the Heart-to-Heart column for address.
The Pemphigus Vulgaris Foundation is a 501(c)3 charitable organization. Our goals and objectives:

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

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 Vulgaris 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.

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Many of us have experience with various aspects of Pemphigus. The purpose of this column is to put people with questions in touch with those who may have answers or suggestions. This is intended to be experiential advice only, and should not be misconstrued as medical advice. Please consult your practitioner if you have any questions.

1) My medicine (Prednisone) tastes terrible. Do you have any ideas on improving the taste?
   Try putting the tablets in gel caps. Gel caps are available at most health food stores and some pharmacies for 2-6 cents each.

2) I'd like to search the world wide web for Pemphigus information, where can I start?
   Try the Lycos search engine: http://www.lycos.com
   or Alta Vista: http://www.altavista.digital.com
   Both of these searches produce 100 or more articles about Pemphigus. Virtually all of the search engines will produce some usable results (hits) because Pemphigus is an unusual word.
   http://www.avicenna.com is a medical database with articles about Pemphigus. Entry is free, but you have to register with a user name and password.

Questions for the next edition:

If you know an answer or have a suggestion, please send them to the Foundation via mail or E-mail:

1) I have PV on my scalp. What can I use as a shampoo?

2) Are there any bath additives that can ease the pain of open skin blisters?

3) Can anybody locate a copy of the book: “Heal Me or Kill Me” by Cornelius F. Range? It's an autobiography of the spiritual journey of a man during his healing from Pemphigus Vegetans.

Do you have a question? Send it along and maybe somebody knows the answer.

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