The Use of Minocycline as an Adjuvant Therapy for Patients with Pemphigus Vulgaris and Pemphigus Foliaceus

Source: "Minocycline is a Useful Adjuvant Therapy for Pemphigus" Zoran S. Gaspar, Valerie Walkden, and Fenella Wojnarowska Department of Dermatolgy, The Churchill, Oxford Radcliffe Hospital, Headington, Oxford and Department of Dermatology, Wexham Park Hospital, Wexham, Slough, Berkshire, U.K.

Dr.'s Gaspar, Walkden, and Wojnarowska conducted a study looking at the use of minocycline, as an adjuvant therapy for patients with Pemphigus Vulgaris and Pemphigus Foliaceus. The patients who agreed to be a part of this study attended their outpatient clinic for bullous diseases. Patients were treated from 1987 to 1995 with 100 mg. per day of minocycline. All the patients had active disease prior to the introduction of minocycline.

Prior to the study, all patients showed active disease. How the patients responded was measured by their clinical improvement and the ability to reduce immunosuppressive drugs.

The clinical improvement was divided into four categories:
1) definite major - no new lesions and total clearing.
2) definite minor - improvement of disease activity but still some new lesions.
3) equivocal - response not in keeping with timing of minocycline introduction.
4) no response.

RESULTS: There were 10 Pemphigus patients treated with minocycline from 1987 to 1995, with an age range of 19-80 years. Seven patients had Pemphigus Vulgaris and three patients had Pemphigus Foliaceus. Four patients were on a combination of prednisolone and azathioprine, five patients were on prednisolone only and one patient was on azathioprine only.

The dose of prednisolone ranged from 10 to 40 mg. and the dose of azathioprine ranged from 100 to 200 mg. Patients had not received other systemic therapy. Assessment of patients by subjective clinical improvement revealed four definite major, two definite minor, one equivocal and three non-responders (Table 2). Post minocycline, the prednisolone dose in the six definite responders were 0 mg. (in three patients) to 6 mg. The average decreases in prednisolone dose was 21 mg. and the average time to response was 8 months.

Post minocycline, azathioprine was stopped in two patients and reduced from 150 to 50 mg. in the other responder. In the equivocal and non-respond-
I want to dedicate this issue of The Pemphigus Foundation News in the memories of Alita Wood and Neal Furby. Both Neil and Alita died this past month from side effects of their medications. They were both wonderful and kind people, wanting to be involved with helping others with Pemphigus. Alita had just turned forty. She developed a fungus in her lungs and heart and, immediately after surgery, had a brain aneurysm.

Every time I talked with her and, in spite of her pain and discomfort, she remained optimistic and positive. Neil suffered for many years from prednisone side effects, but still he wanted to be a part of a Southern California support group. He lived a full life and died in his eighties. I know that both Alita and Neal would not want anyone to worry that because they had suffered specific problems, it would happen to you. Alita wrote this letter to me a year ago. She wanted me to put it in the newsletter so that people could contact her in the Southern area. We talked about holding the letter until she recovered and could begin to take calls again. I want to share this letter with you.

Dear Janet, I am writing this letter to share with you and all the others who are like us and have a daily companion called Pemphigus Vulgaris, that we did not choose to have, some of my experiences, rejections and finally acceptance of this disease. When I was diagnosed December 27, 1995, I had never heard of or knew that such an illness even existed. So, immediately I started searching for all the information I could find. Thanks to my aunt and modern day computers, she found out about the PV Foundation through the Internet. After talking with you and getting the newsletters, reading articles out of medical journals and other literature and information that I could locate, I could not believe that I had such a disorder as this.

So, I guess you could say that I went into a very denial period that this was happening to me. I have always been a very hyper person, so I decided that I didn't have a health problem and I would prove it. I completely redecorated my house. I painted. I cleaned out closets. I floored the attic. I cleaned out dresser drawers! There was nothing in my house that was not moved!! My 17 year old son came home one day and asked me when I was going to start building the new room and digging a basement. I thought as long as I could do all these things that the PV would go away and I could ignore it. I tried so hard to keep the pain and anguish away from my family and friends. I have never been sick, except for the common colds and things of that nature, and I was not going to start now.

But, to my surprise, I was not hiding it from myself either. I started out on 40 mg. of prednisone a day, which before long had to be increased. I would take my medication, go to bed at night thinking I would get up in the morning, be lots better, only to find I was not any better, but actually going down hill. I was experiencing all the ill side effects that the prednisone had to offer. The PV has effected my voice and I never know how my voice is going to sound when I start to speak.

But, at any rate, from the 27th of December until April 3rd, I was in total denial that I had this problem. On April 22nd, I developed a secondary infection and had to be rushed to the emergency room. I knew I was terribly sick and had to get the necessary help. I have a fantastic doctor here in this small town that I live in, whom I see on a weekly basis. He gave me some very strong antibiotics and let me return home.

The next morning I was still not any better. I am a Christian person, and the morning of April 23rd, I turned everything over to the LORD. From that moment on, I have been showing signs of improvement. I have expected that I have this health problem and that I am going to deal with it and handle it.

As I mentioned, I have a won-
derful doctor here. He has conducted a tremendous amount of research on Pemphigus Vulgaris and also thanks to you giving me Dr. Grant Anhalf’s phone number, my doctor, Dr. William Jennings, has been in contact with him. I started on Imuran three weeks ago, and hopefully this Wed., June 5th, 1996, I can start cutting back on the prednisone.

I honestly feel that a large majority of my problems are generated from the medication. I know that my letter sounds depressing, but I’m not meaning for it to be. There is a lot of negativity with PV, but it can be overcome.

I have found through trial and error several things that have helped me and if I may I would like to share them. A hot tub is great to help with the soreness, stiffness and joint aches and pains; also, massage therapy. If where you live, in an area with high humidity, I have found that using Eucalyptus in the house, as well as Eucalyptus Oil in a Potpourri Pot really helps my breathing. Also, rice bags scented with natural herbs and spices, heated in the microwave help with the aches and pains. I have been on as high as 120 mg. of prednisone daily and had to stay at that level dosage for four weeks. Now, I am back down to 60 mg. daily.

I have good days and I also have bad days, which I think we all do. It is just something we are going to have to learn to live with. I know that there are several support groups nationwide. However, I don’t think there is one here in the South. I would love to head up a support group for anyone in the Southern and Northern States that would be interested in communicating with me. I feel like it is so beneficial to be able to talk or write to people who know what you are going through. My family and friends have been so very supportive and loving through all this, but yet and still, they really cannot relate to what we are actually feeling, mentally and certainly not physically.

Janet, feel free to use my letter. I am just thankful for people who take the time to talk, listen and be a friend when we need one.
We have changed our name to The Pemphigus Foundation. We do not want people with other forms of Pemphigus, such as Pemphigus Foliaceous to feel excluded from our help and support.

Washington Trip Report

The Foundation joined the Coalition of Patient Advocates For Skin Disease Research (CPA/SDR). The main focus of the group is to educate Congress on how important it is for them to support research in the area of skin diseases. The National Institutes of Health is divided into several divisions. We went to Washington to support The National Institutes for Arthritis, Musculoskeletal and Skin Diseases (NIAMS), a division of the NIH.

The Pemphigus Foundation was represented in Washington by Janet Lehne. It was a two day event. The first day, we went to Bethesda, the home of the NIH, and toured the NIH Library. They gave us information on how to use the NIH software so that we can access information from the Library successfully. They talked about updating their program so that it will be available on Windows as well as in DOS.

We were then met by Dr. Stephen I. Katz, M.D., Ph.D., Director of NIAMS. Dr. Katz discussed with us his testimony on the hill, fighting for a 9% increase in funding for the NIH. He told us that about 20% of applications for research grants submitted to NIAMS were approved. He would like to see that number increase to at least 25%. Before coming to the NIH, Dr. Katz did research on Pemphigus. We applaud Dr. Katz’s commitment to finding a cure and/or better treatment for Pemphigus as well as many other debilitating diseases.

In the evening, we had a CPA/SDR dinner meeting where we discussed the procedures for the next day. On the second day, we had a breakfast meeting with all of the organizations supporting NIAMS. We met at the Capitol Hill Club (which is a Republican Club). We listened to speeches from a Congressman (also doing a little politicking), Dr. Katz, and an expert on appropriations. We then had lunch and proceeded to our respective Congressional representatives to discuss with their staff why we would like for them to support the 9% increase in funding to the NIH.

As our office is located in Berkeley, California, Janet went to Representative Ron Dellums’, Senator Barbara Boxer’s, and Senator Dianne Feinstein’s offices. We were treated with respect, and Rep. Dellums representative told us that Dellums was not only supporting the increase in these years NIH budget, but is introducing a resolution to double the NIH funding in the next five years. Rep. Dellums came into the office after he had finished a meeting and agreed to take the time for a picture with Janet and her daughter. We informed our Representatives about Pemphigus (of course they had never heard of it) and they showed genuine interest in learning about our disease. We want to thank all the California representatives for their kindness and attention.

The American Academy of Dermatology Convention

Because of our connection with the Coalition, we were able to have a table at the AAD Convention held this year in San Francisco. We were represented by Janet Lehne, Gail West, and Alice Hammel. We want to thank all the people in the San Francisco Bay Area who offered their time. We offered our brochures (new ones with The National Pemphigus Foundation name) and our past newsletters. Over 100 newsletters and brochures were handed out. We want to thank all those Dermatologists who stopped by.

Continued on next page
our table and talked with us about Pemphigus and other related subjects.

We met with doctors from all over the world. Many physicians who stopped by were glad to see that a Foundation existed and promised to tell their patients that we are here for support. Next year’s AAD meeting will be in Orlando, Florida starting the end of February. We will hopefully be able to present ourselves at this meeting as well.

Other News

Our friend Victor Leitehman in Israel is working on a website. The URL (address) is:

http://www.geocities.com/HotSprings/7445

This website links to many medical resources, including the site being developed by Steve Shapiro focusing on alternative therapies and diet.

HELP! We are looking for a logo, and would like your input. Send us your ideas.

As many Spanish speaking physicians stopped by at the convention, we are looking for someone who would be willing to translate our brochure into Spanish. Please contact Janet if you feel that is something you would like to do.

Stuart Grossman is interested in the following information on patients drug history and results as follows:

- Location of lesions
- History of medication dosages used
- Amount of time on the medication
- Results

He will supply the information that he collects back to anyone who requests it. However, he will not give out any names of patients who have supplied the information to him.

Janet Lehne will be in the New York City area from May 19th to June 11th. She will be picking up her phone and e-mail messages frequently. Check the heart to heart section for information on contacting any of the people mentioned above.

Alternative & Natural Healing

Steve Shapiro

Greetings! The last few months have been very exciting. As I write this, I’ve just concluded my first real experiment at controlling Pemphigus without drugs, and am preparing to start another experiment shortly. I have learned a lot of information about Pemphigus and myself during this process.

To review: when I was first diagnosed and treated with Prednisone in 1995, I set a goal for myself to live without PV and the drugs used to control it. In this article, I’d like to share some of the things I learned, and the processes I’ve gone through and am going through.

The first thing I did was look and listen. I listened to people’s stories about how they have lived with Pemphigus. I listened to stories of people going into remission, and of people dying. I gathered stories of people being helped by B vitamins, herbs, avoiding leaks, and possible links to garlic & onions. I noted cases of Pemphigus apparently induced by drugs or environmental conditions.

I noted similarities between Pemphigus and other inflammatory autoimmune conditions. I read countless books, journal articles and research papers. I even understood a few of them! I linked up with organizations such as the National Organization for Rare Diseases. This information became like pieces of a jigsaw puzzle. I know what the final picture will look like, but I don’t know how many pieces are included.

Several things became clear, if I were to achieve my goal I’d have to:

Actually do something to facilitate it. Rather than pining my hope on formal medical research, I will have to be proactive in healing my own body. To date, medical science has advanced to the point where we can occasionally control the symptoms of autoimmune disease, but not heal the underlying cause. There is no reason to assume this situation will change in the near future.

Change my frame of reference. I adopted the position that something(s) was/were causing my PV. Those things, which I’ll call instigators, were acting in combination with my genetic structure to produce

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ers, there was no clinical improvement with the addition of minocycline and alternative changes in therapy were necessary.

Nine patients suffered from candidiasis after the introduction of minocycline. One patient developed hyperpigmentation and the dose was reduced from 100 to 50 mg.

DISCUSSION: We have shown by the present retrospective study, although not statistically significant, that 60% of our patients had definite subjective clinical improvement. Two of the patients were able to totally discontinue their pre-minocycline oral treatment and the other four patients had significant reductions in dosages of prednisolone and/or azathioprine.

As the side effects of these drugs are dose dependent, this reduction of dose is a great benefit to the patient. The following possible side effects for minocycline are stated in the British National Formulary: nausea, vomiting, diarrhea, dizziness, vertigo, exfoliative rashes, pigmentation, headache, visual disturbances and reported cases of liver damage, pancreatitis and pseudomembranous colitis.

Only one of our patients had problems with pig-

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* time to response, in months

mentionation; nine had problems with candidiasis; however, cessation of therapy was not indicated as these side effects were well tolerated and easily managed. A prospective double blind controlled study in the use of minocycline in these patients is warranted to assess its benefits or disadvantages.

However, from our small series of patients, we conclude that minocycline 100 mg. daily is a simple, safe and well-tolerated treatment that should be tried in patients with Pemphigus to reduce disease activity and/or the dose of potent immunosuppressives and/or corticosteroids.

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.

P.O. Box 9606
Berkeley, CA 94709-0606
(510) 527-4970
Fax (510) 527-8497
E-Mail: PVnews@aol.com
Fosamax is Here!

Lee A. Heins

The powerhouse drug giant Merck and Co. has recently introduced a new anti-osteoporosis drug called Fosamax (Alendronate Sodium). This is one of the first major new breakthrough drugs characterized by easy dosing, few side effects and predictable results. During 1996, the company sold $200 million in product with an estimate of $1 billion by the years 2000.

This new molecule is classified as an aminobisphosphonate that binds to bone hydroxyapatite and specifically inhibits the activity of osteoclasts, the bone-resorbing cells.

Fosamax reduces bone resorption with no direct effect on bone formation, although the latter process is ultimately reduced because bone resorption and formation are coupled during bone turnover. Fosamax thus reduces the elevated rate of bone turnover observed in persons taking prednisone to approximate more closely those not taking the drug.

The standard dose for those taking small to moderate amounts of prednisone is 10 mg. of Fosamax daily. If large doses of prednisone are being administered, up to 40 mg. of Fosamax per day may be prescribed. The dose is usually administered orally with very specific but simple dosing instructions.

This medication is to be taken upon rising in the morning. Exactly thirty minutes before the first juice, coffee, food or other medication. A full glass of water (8 ounces) is taken with the swallowed drug in order to prevent local irritation of the upper gastrointestinal mucosa or ulceration of the esophagus. Finally, one must not lie down for the thirty minutes time period before eating breakfast. When these steps are properly taken, I experienced virtually no noticeable side effects.

The easiest way to test for osteoporosis is with a bone density scan. In the case of someone taking large doses of steroids daily, osteoporosis may be observed in a simple X-ray of the spine. Merck is helping to develop a urine test for osteoporosis that should be available soon. Anyone taking in excess of 10 mg. of prednisone daily should assume that they may have a tendency to be osteoporotic and should discuss their specific case with their physician.

In addition to Fosamax, supplements containing calcium, magnesium and vitamin D along with weight bearing exercises are recommended. Fosamax is presently approved and is being heavily marketed to post-menopausal women and patients with Paget's Disease (rare bone disease).

The cost of the drug is about $60.00 per month at retail. If you are part of an HMO you may obtain the drug after paying your standard drug co-pay. However, be prepared to challenge your health provider for the right to take this medication due to its present narrow indications.

Merck’s Fosamax drug trials that utilized 10 mg. per day increased bone mass in the hip and spine (by 7.2% and 8.2% respectively) and reduced the risk of vertebral fractures by 48% compared with the placebo. Future test groups will include males and users of prednisone for autoimmune diseases and asthma.

Although the drug is not specifically indicated for steroid users, physicians may still prescribe the drug as long-term steroid use approximates the condition of a post-menopausal female. Therefore, this new drug is possibly a requisite for most long-term steroid users as it prevents the serious bone fractures associated with osteoporosis. Fosamax should dramatically improve the Pemphigus patient’s bone mass that will in turn lead to an improved quality of life.

This article is based on Lee's personal experience and each individual needs to consult with their physician on the possible side effects and/or applicability of the drug for them. The information given is not medical advice nor is it presented as a personalized course of treatment. Lee welcomes your comments.

We've got a new address
PO Box 9606
Berkeley, CA 94709-0606
aberrant antibodies, which in turn attack my skin. I knew that to stop the reaction, I'd have to find out what those instigators are. Two quotes stand out that exemplify my position: "If you’re falling off a cliff, you may as well learn how to fly" and "If you continue to do what you have always done, you will get the same results you have gotten."

Find peace with myself. Traditional medicine uses a very militaristic approach, using terms like battle, victim, attack, etc. Rather than continue to instigate my immune system to improper behavior and then suppress it with drugs, I came to believe that my immune system will stop attacking me once the instigators were removed.

Be willing to accept what I find and change my life accordingly. This is the most difficult part. It is proving to be the most important. I also had to be forgiving toward myself and the doctors treating me for making mistakes. Pemphigus, as most autoimmune illnesses, is very poorly understood, and often does not do 'as it is supposed to.'

For brevity, I'll limit my discussion to what I've found and what I've done, and skip the background information on how I found it.

The first questions I asked were: How can I lighten the load on my immune system and body in general in order to lessen the severity of Prednisone side effects and how can I start to determine what instigators enabled the Pemphigus to develop?

The first thing I did was to change my diet. I was already a vegetarian and consume very little dairy. I further reduced dairy consumption, stopped eating fried foods and foods containing simple sugars. Sugar impairs digestion, weakens the immune system, and pulls calcium from bone tissue, contributing to osteoporosis, as does dairy consumption. Heated oil contains large amounts of deleterious free radicals. I also started eating organic foods as much as possible. I tried to eat food raw, as opposed to cooked, in order to maximize my nutritional intake. During the times I was unable to chew, I used a blender to puree my food. I noticed a sharp decline in noticeable side effects from Prednisone during this time.

I started a series of rather obscure medical tests, administered by doctors of naturopathy. The most important clue came from an IgG4 food immunology blood test. This is an allergy test wherein a sample of my blood was tested against common foodstuffs for immune reactivity. The test showed that I was reactive to many foods that I was eating every day. I usually got PV outbreaks in my mouth while I ate, even when my Prednisone dosage was at 30mg every other day. The very first meal I ate that was free of these "allergic" foods caused very little PV reaction. I knew I was finally on to something.

During the next eight month period, by eating monomels, a meal of as much as I wanted of only one item, I was able to find that I had immediate reactions (growths in my mouth) to some foods and not others. In addition, any skin blisters I had would become more viscous within a few of hours after eating some foods and not others. I concluded that there must be some common item or items in these foods that was causing the reaction. My next step was to identify the common component.

I looked at many possibilities, including protein, vitamins, minerals, and fatty acids. My research eventually led to a group of compounds called phenolics. Phenolics, generally speaking, are molecules, manufactured by plants, that provide taste, color, aroma, and immune-protectivity for the plant. There are approximately 200,000 known phenolic compounds.

Normally, we metabolize these compounds in our livers and kidneys. They are extremely important in protein synthesis and hormonal processes. For some reason, my body reacts violently to at least six of the compounds, causing a reaction that I believe causes Pemphigus. This was a revolutionary find. I proved the theory on myself by finding and eating foods that do not have any of the compounds to which I react. During this short test period I did not get any reactions in my mouth or on my body. Now, I was finally onto something, but there are two problems with this theory. First, there is limited and often conflicting data available concerning which compounds are in which foods. Second, the compounds I am reactive to are found in most foods, and avoiding them was causing me to become malnourished. Eventually, I had to start eating foods containing the compounds to which I am reactive, and my Pemphigus started coming back.

During this first experiment, I was able to make some progress, but was unable to completely control the reaction. I decided to stop the experiment and resume taking Prednisone until my tissues have had a chance to repair themselves. I plan to restart the experiment as I am able. ☺

This article represents Steve's personal experience. The information given is not medical advice nor is it presented as a personalized course of treatment.
New York Support Group Meeting
Joan Delucie

The National Pemphigus Foundation, New York Chapter Support Group held its first meeting on Sunday, January 26, 1997. We all feel very fortunate to have the support of two dermatologists from New York University Medical Center, Dr. Jean-Claude Bystryn and Dr. Joyce Rio. The members agreed the meeting was a wonderful way to start the New Year. Five members and three of our spouses were present. The goals we established are to first and foremost provide support to our members and their families.

Some other goals will be to educate, inform and organize fund-raisers. We plan to send an introductory letter and the Foundation brochure to dermatologists in the New York Metropolitan area. The purpose of this material is to inform the Dermatologists and their patients about the Chapter and the Foundation.

At our next meeting on March 2, 1997, information will be made available on Medic Alert bracelets and EMX Health Cards. For information about the New York Chapter Support Group, or if you need help starting a group, please call me and I will help in any way I can.

The second meeting of the New York Support Group was held on Sunday, March 2 and led by Sandra Feldstein. I am pleased to report that we have five new enthusiastic members. We discussed the radio broadcast and the announcements about the NY group that were sent to weekly newspapers and TV bulletin boards. Information was handed out on the MedicAlert bracelet and on the EMX universal health card. Members will review the material and the topic will be discussed at our next meeting. The introductory letter I prepared to dermatologists in the NY Metropolitan area was reviewed by the members. Mark Grossman will make some revisions and have it ready for our next meeting.

Matt Koneig and I will begin work on a “Do and Don’t” brochure for PV sufferers. Dr. Bystryn offered to review it before we have it printed. He also offered to address the group at our May meeting. In addition, there is an oral pathologist at Long Island Jewish Hospital, Dr. John Fantasia, who may also be willing to address the group. Mark Grossman is checking into it. Everyone agreed the meeting went very well. Once again, I would like to thank our significant others for attending the meetings and even more importantly, for their continued support. The groups next meeting will be held on Sunday, May 4, 1997.

San Francisco Support Group

The first meeting of the SF Bay Area Support Group was held in Berkeley, California on February, 24th. We had eleven attendees; two who did not have Pemphigus. We mainly introduced ourselves and talked about what we have experienced and ways in which we can help and support each other. We discussed what positive steps we could take in avoiding drug side effects, and stress. We are planning another meeting for the first weekend in May.

Philadelphia Support Group
Miriam L. Schneidmull

The February meeting of the Philadelphia Support Group was attended by about fifteen patients and their spouses. We were treated to a discussion of nutrition and diet led by Lisa Unger, MD, a nutritionist and Randi Cardonick, a dietitian. Their focus was on the effects of prednisone and the ways to handle “sore mouth”. To combat the weight gain often associated with steroids, they suggest a diet high in grains and complex carbohydrates and distributed a copy of the food pyramid. To combat the hunger that causes the weight gain, they suggest munching on vegetables. The topic of triggers of oral lesions came up again. Some of us believe that certain foods trigger lesions, or cause them. Others think that lesions are discovered by the hot/spicy/acidic foods. What do you think? Do any of you believe that certain foods trigger either oral or other lesions? Drop me a note, snail mail or email and let me know. The next meeting is tentatively scheduled for May 9 (changed from April 25). We will have the chance to “write away” our concerns about our health or Pemphigus or anything else under the direction of Michele Bernstein who is a Certified Journal Instructor. For those who are not interested in writing, coffee and cookies and socialization will be available in the outer room.
Thirty Years After

David Zaret

It was July, 1966. LBJ was President, Sandy Koufax was in the process of winning 27 games for the Dodgers, and the first moon landing was three years in the future. I myself was eighteen years old, working as a day camp counselor, and looking forward to beginning my freshman year at Reed College in September. I was also becoming aware of a few strange lesions in my mouth that refused to heal. I tried to ignore them. By the beginning of August the oral lesions were worse, and I had started to develop blisters on my skin. By the end of August, I found myself at the Mayo Clinic, where I was pronounced the third youngest Pemphigus Vulgaris patient ever seen at the Clinic.

I never did make it to Reed. Alas, I didn’t tolerate the prednisone therapy very well at first. So my dose was tapered too quickly, leading to a new flare-up a few months after the first one. For a while, I was caught up in a most discouraging cycle: hospitalization for a flare-up; home for a while; hospitalization for steroid side-effects; home for a while; hospitalization for a flare-up. After a year of this, however, my condition stabilized, and I was able to taper my prednisone dose slowly over a period of two years—until I was at a comfortable maintenance level.

I have only suffered one other flare-up, in the early 1970’s—but that was a bad one. 40 mg. of prednisone every six hours wasn’t sufficient to get things under control, so I was finally given Imuran as well. The combination of drugs did the trick, but I still spent many months in the hospital. I have never managed to go off the prednisone completely; so I have now been taking the stuff, without a break, for more than thirty years. But for most of that time, I have been on a reasonable maintenance dose of 10 mg. every other day.

Despite the prednisone, I have managed to graduate from college and graduate school, get married, have children, go through a couple of career changes, and survive a mid-life crisis. In short, I have managed to live a “normal life.” I also stay physically active, playing tennis or squash a few times per week. This is a good way, I think, to help ward off some of the obnoxious long-term effects of steroid therapy.

One thing my parents and I sorely lacked, especially during the first few years of my illness, was any sort of support group. In fact, when I spoke with Janet Lehne over the phone two years ago, it was the first time I had ever spoken to another Pemphigus patient! So I greatly appreciate the efforts Janet has made in establishing the PV Foundation. I look forward to corresponding with others who are trying to come to grips with PV.

Would you like to share your experiences? The Foundation welcomes articles from all people living with or affected by Pemphigus, and will print as many of them as space permits.

Bright Ideas

Continued from back page

are some 12 reported cases of Pemphigus developing from or aggravated by penicillin.

To date, nobody has been able to locate a copy of “Heal Me or Kill Me” by Cornelius F. Range. If anybody does find a copy of this man’s autobiography of living with Pemphigus, please let us know.

Questions for next month: Can you help answer any of the following questions?

- How can I start a support group where I live?
- Which toothpastes are best for ulcerated mouths?
- How many people have Pemphigus, and how many forms of Pemphigus are there?

Do you have a question about living with Pemphigus or, have you found something that you’d like to share with others? We welcome your questions and comments, and will print as many as space allows.
A Look Toward Our Future

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.

Janet S. Lehne
President/Executive Director
The National Pemphigus Vulgaris Foundation
P.O. Box 9606
Berkeley, CA 94709-0606
(510) 527-4970
E-Mail: PVnews@aol.com

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Do you have a question about living with Pemphigus? Maybe somebody has an answer. Send in your questions, and we’ll publish them in the next edition, and who knows, maybe you’ll have an answer for somebody else’s question!

What shampoos can I use for my scalp lesions?

From Bill in New Zealand - My shampoo is 3% cetrimide (antiseptic), 5% glycerine in plain water. This has always been completely harmless to me and, being watery, is easy to use. You can add some rose-water if you hate the smell. My baths in the hospital were potassium permanganate solutions. This works as an antiseptic, and helps to dry out any wet, open lesions. Solution should not be too strong but this can be judged by the color (Just a pale pink). It will turn brown after you’ve been in it, by an oxidizing reaction with yourself. You are advised not to drink the bath-water, or get it in your eyes. Side effects from repeated use are: brown toenails and possibly, a brown bath. If your skin/hair starts turning brown too, you are using too much!

Also suggested as a shampoo if you have lesions, Poly Sorbate 80 shampoo from Twin Labs.

Upon reading Dr. Brenner’s article on thiol drugs, if I get a bacterial infection, should I ask my physician not to give me Penicillin as an antibiotic?

Based on her study, we asked Dr. Sarah Brenner on her thoughts about using Penicillin as treatment for bacterial infections. The questions asked was: “Does Penicillin cause or aggravate Pemphigus?” Her statement to us was: “It most certainly can! Penicillin is related to D-penicillamine. It is a masked thiol drug with an S in its molecular structure that can change into SH. There

The National PV Foundation
P.O. Box 9606
Berkeley, CA 94709-0606

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