SAVE THE DAY!
The 10th Annual Patient/Doctor Meeting will be held in Toronto, Canada from September 15-16, 2007. See Back Cover for more details.

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Boston Support Group Spreads Awareness at YDC

Yankee Dental Conference® 32
January 24-28, 2007
Boston, Massachusetts

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The International Pemphigus & Pemphigoid Foundation is a 501(c)(3) nonprofit organization.

Our goals are to increase awareness of pemphigus and pemphigoid among the public and the medical community; to provide information and emotional support to pemphigus or pemphigoid patients and caregivers; to provide referrals to specialists; and to support research into advanced treatments and a cure.

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Rituximab: A New Treatment for Recalcitrant PV?

by A. Razzaque Ahmed, M.D.  
Center for Blistering Diseases  
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Rituximab (RTX) is anti-CD20 chimeric antibody that selectively targets B cells. CD20 is a molecule that functions as an antigen for it. CD20 is expressed on mature antibody producing B cells, but not on plasma cells. (1) The FDA has approved the use of Rituximab for the treatment of B cell lymphomas. (2) Since the pathogenetic and clinical manifestations of PV appear to be antibody related, it could be hypothesized that eliminating the pathogenic antibody and the cells that produce it, might be more effective than general nonspecific immune suppression. This is the rationale for using Rituximab in treating pemphigus vulgaris. Indeed, success with the Rituximab has been observed in many autoimmune diseases which are mediated by antibodies such as systemic lupus erythematosus and immune thrombocytopenic purpura. (3)

In a recent review of the available published literature in the English language on Rituximab was done. (4) There were 17 patients presented in ten different studies. These patients had been treated with RTX using the lymphoma protocol. In this protocol, patients are given four weekly infusions. The dose is 375 mg/m2 for each infusion. The results were variable, but overall it appeared that 88% of the patients were free of lesions, for at least a six months follow-up period. Unfortunately, many of the patients were treated simultaneously with conventional immunosuppressive therapy (CIST). In many of them, the use of RTX allowed for lowering the dose of Prednisone. One of the major problems associated with RTX in these patients was infection. Four patients had serious infections and in addition one patient died from it. None of these patients got intravenous immunoglobulin (IVlg).

Since the cumulative literature supported the use of RTX in producing a positive clinical outcome, we decided to study the use of RTX in recalcitrant pemphigus vulgaris. Our major concerns were (i) can the use of RTX eliminate conventional immunosuppressive therapy, and (ii) could RTX therapy produce prolonged and sustained clinical remissions. Recently we have published data on 11 patients in the October 26, 2006 issue of the New England Journal of Medicine. (5) To the readers of the Quarterly, it would be important to identify the group of patients we studied by providing some key characteristics. The important features of this group were that they all had been treated initially with Prednisone and other immunosuppressive agents. The mean daily dose of Prednisone was 125 mg. All had been treated with mycophenolate mofetil, 10 with azathioprine, 9 with methotrexate and 6 with cyclophosphamide.

Since the patients did not respond to conventional immunosuppressive therapy, they were subsequently treated with IVlg. The IVlg was not totally effective. To augment the effect of IVlg, Dapsone with methotrexate continued on page 6...

Anti-TNF Therapy for Mucous Membrane Pemphigoid

by Michael P. Heffernan, M.D.  
Associate Professor of Dermatology  
Div. Chief & Residency Program Dir.  
Wright State University, Boonshoft School of Medicine

Mucous Membrane Pemphigoid, also known as Cicatricial Pemphigoid, is a serious autoimmune blistering disorder that can result in blindness and other complications as the result of scarring of the mucous membranes. To our knowledge, there have been 2 reported uses of Etanercept for MMP in the literature. In the October and November editions of the Archives of Dermatology, we reported on our experiences with 4 additional patients. Three responded to treatment with Etanercept 25mg twice a week and one who responded to Infliximab at 5mg/kg at weeks 0, 2, 6, and every 8 weeks thereafter. All of our patients had failed prior standard treatments.

All of our patients responded rapidly and their response persists. We did have 1 patient whose disease recurred when she stopped therapy. Fortunately, she was able to regain control with retreatment. Since the publication was submitted, we have treated 2 additional patients with Etanercept with the same results.

Additional cooperative, prospective studies are needed to confirm these results. I plan to propose this study at the next meeting of the Medical Dermatology Cooperative Trials Group (http://www.meddermsociety.org/). I hope that the use of Anti-TNF therapies for MMP will teach us something new about blistering diseases and help us to identify more effective and safer treatments for our patients who suffer from them.

For more information feel free to contact Dr. Heffernan at michael.heffernan@wright.edu.
Is Pemphigus More Common in Women?

Pemphigus may be Affected by Hormonal Intake

by Sarah Brenner, M.D.

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Tel Aviv-Sourasky Medical Center, and
Tel Aviv University Sackler School of Medicine, Israel

The International Pemphigus & Pemphigoid Foundation recently conducted a survey for us on some aspects of pemphigus, in particular the gender distribution of the patients, and the relationship between the disease and the use of sex hormones. A total of 249 members of the Foundation answered a short questionnaire on their gender, the age at which they developed the disease, and whether they were taking hormones when it began. There were 151 women and 91 men, a female: male ratio of 1.7:1.

Is there indeed a predominance of women among pemphigus patients? Or are women simply more responsive to questionnaires?

If these numbers do reflect a female predominance, we would like to address the possible reasons. A major factor is the involvement of the immune system in the course of the disease that makes women more susceptible to this and other autoimmune disorders. Sex steroids affect how the immune system develops and functions differently in men and women. The currently held view is that androgens, the male hormones, are anti-inflammatory and depress immunity, while estrogens, the female hormones, enhance it. The result is that women have a greater immune response to external agents. It is known, for instance, that females are more prone to develop autoimmune diseases like systemic lupus erythematosus (SLE) and multiple sclerosis, while males tend to develop lupus later in life or due to disturbed hormonal regulation.

Indeed, more than 75% of patients with autoimmune diseases are women. Thus, it is clear that hormonal make-up renders women more likely to develop pemphigus than men. A second factor in the preponderance of women among pemphigus patients is the strikingly high proportion of users of hormone replacement therapy (HRT) found among postmenopausal women. In the survey, 20 of the 43 postmenopausal women were on HRT at the time they developed the disease. The immune system of women is exposed to estrogens in a number of ways, some internal like the natural estrogenic hormones produced in conditions such as pregnancy. But, estrogenic hormones can enter the body from outside as well, for medical reasons like replacement therapy and contraception, or via environmental agents such as plastics, pesticides, plants, and the like.

Almost every second woman after menopause in the survey was consuming some form of sex hormone. This finding is higher than the 30% figure for hormone replacement therapy documented in a 2001 study of all adult women in the United States and the United Kingdom. Do these figures argue for the role of hormone supplements in the disease?

Another interesting finding is the use of hormonal supplements in 4 out of the 91 men in the survey. The purpose of this hormone intake by men is unknown and has not been addressed in the medical literature. Epidemiological studies are needed to assess the extent of this phenomenon among men, but one can speculate on a trend of treatments for male menopause (andromenopausing) or anti-aging. Does testosterone intake play a role in pemphigus? This finding merits further study.

We wish to express our special thanks to Janet D. Segall, Interim Executive Director and Director of Patient Services, and Will Zrnchik, Director of Development and Communications, of the International Pemphigus & Pemphigoid Foundation for conducting the survey discussed here. We would like to thank all those who answered the survey, and look forward to more such service in the future.

References

...continued from RITUXIMAB, page 4

was added to the IVIg. The mean duration of all previous systemic therapy, prior to the use of Rituximab, was 68.8 months, indicating that the disease had been present for 6 – 7 years and had not responded to all of the known therapies for PV. These patients also had extensive disease involving the skin and multiple mucous membranes. The patients were treated with RTX in a newly designed protocol never published before or used to treat any other disease. The patients were given the same dose of RTX as in previous studies (375 mg/m2). The protocol was as follows:

Prior to the initiation of RTX, the patient’s got one cycle of IVIg. Then during the first month of therapy, for the first three weeks, they received weekly infusions of RTX. In the fourth week, they received one cycle of IVIg. This same procedure was repeated in the second month. In the 3rd, 4th, 5th, and 6th month, the patients received only one infusion of RTX followed by one cycle of IVIg. Hence, the patients got a total of 10 infusions of RTX in this particular protocol.

Shortly after the initiation of RTX, the patient’s B cell counts were reduced to zero. Hence, the IVIg was given primarily to assist preventing infection. In addition, it was also used as an immunomodulatory agent. It was hypothesized that if the pathogenic antibody and the cells producing it were no longer present, this would provide the immune system an opportunity to regulate itself to the predisease state.

Indeed all of the 11 patients have stayed in remission. The mean duration of remission has been 31.1 months. Two patients had recurrences. In both patients, the recurrences were treated with only RTX and the patients went into a prolonged clinical remission.

It is critical to be aware of the fact that RTX warrants the very rigorous prescreening procedure. Prior to initiation of RTX therapy, we have always obtained clearance from the primary care physician of the patient. In addition, an oncologist has evaluated the patients requiring a CT scan of the neck, chest, abdomen and pelvis to exclude any existing lymphomas. Evaluation of liver and kidney functions and the serological tests for various infections was done. During the RTX therapy, CBC’s, chemistries, but most importantly, peripheral blood T & B cells were monitored on a very regular basis. Until the B cells have returned to normal, monthly infusions of IVIg were given. Once the B cells returned to normal, the IVIg protocol was completed in which the patients received infusions at 6, 8, 10, 12, 14, and 16 week intervals. We believed this was essential to help restore the immune system to its normal balance. Recurrences have not been seen to date in all of those patients in whom this protocol was completed. Hence the ability to complete the IVIg protocol is an integral component of this therapy and needs to be emphasized when initiating the therapy.

Hence, this study of a limited number of patients clearly indicated that RTX used with IVIg, according to this protocol, produces long-term clinical remission. None of the patients had any serious side effects and none of them developed any infections. Therefore, there is optimism to indicate that RTX would be a valuable form of therapy in treating patients who have recurrent disease who are non-responsive to conventional immunosuppressive therapy and only partially responsive or non-responsive to IVIg therapy. This protocol is certainly not the only protocol that could be effective. Indeed studies in the future might provide valuable information on the use of RTX using different protocols.

In closing it is important to emphasize two issues to the readership. First, that RTX is not for every PV patient. Second, RTX is not a benign harmless drug. Its use can have serious consequences. Experience with the drug is limited and additional studies that must include long-term follow-up are critical. If you think you are an appropriate candidate for RTX, please speak to your dermatologist.

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References

A. RAZZAQUE AHMED, M.D.

Educated and trained at Harvard University, Dr. Ahmed is the Director of the Center for Blistering Diseases. He designed and created the first clinical facility exclusively devoted to the care, education, and total well being of patients with blistering diseases. He has built an accompanying laboratory that focuses on studying molecular mechanisms in blistering diseases. Dr. Ahmed was a pioneer in identifying genes that predispose to blistering diseases. He pioneered the use of IVIg in blistering diseases and singularly negotiated with Medicare in getting national medical coverage for its use. Dr. Ahmed has worked on blistering diseases for 25 years and authored over 250 papers on it.
Psychologically Speaking

with Terry Wolinsky McDonald, Ph.D.
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Loss of Control: Your Choice

Coping with Chronic Illness Starts with Acceptance

No one asks to be "chosen" for chronic illness and/or pain. There are, however, choices you can make which can either "empower" you or allow you to be a "victim" of circumstances beyond your control. It is normal to ask "why me?" but there are no easy answers; it is not because you are a bad person and somehow need to be punished. Sometimes things really do just happen, and in the case of certain diseases and disorders, some people may be genetically predisposed from birth. Scientists are continuing to study this connection, along with stress and other environmental factors. Not feeling you are in total control does not mean you have no control; black and white exist, but most of life is varying shades of grey. In fact, black and white thinking is a very common "cognitive distortion".

After you are diagnosed you will feel emotionally different (e.g., anxiety, depression, anger, irritability, lack of energy, sleep and appetite changes). Sometimes the medications that are used to treat the disease magnify the above changes. Waiting – for the medications to work, in doctors’ offices, hospitals, etc. – will add to the feelings of loss of control. Sometimes we have to miss a lot of work days, which can be especially disconcerting if we define who we are by our work. Changes will be inevitable. It will be important for you to start to accept a certain amount of lack of control over aspects of your life which you previously took for granted. You will adapt by using more positive coping strategies.

First you will come to accept the things you can not control, since none of us has a crystal ball. The serenity prayer used by AA and NA is often helpful here. The future is uncertain for everyone, but not the same as in this new way for you. Your primary support system may or may not be accessible for you in the ways you need it. How do you tell people who are not afflicted in this way how you honestly feel? When someone says, “My you look really good; you must be getting better”, how do you respond? You will want to explain the disease and its unpredictability to them, but will they really get it? Will they be able to understand? Will they want to understand? Can they really handle the truth? If not, and you have not come to terms with the illness yourself, this will be a major problem for you. But, remember, this problem will not take away all of your control unless you allow it to do this.

My own standard response is “thank you” to a compliment and “why don’t we talk about how YOU are feeling?” to “How are you feeling?”. “I’m fine” or “I’m here” may also be appropriate, depending on who is asking the question. My husband, who does not have a chronic illness, has a standard response when asked how he is: He just says “absolutely”. Some people don’t even realize he has not answered the question. For most people, “Hi; how are you?” is just a greeting. They don’t really want to know, so just take it as a greeting and don’t feel obligated to educate them or to get things off your chest unless an exercise in futility and frustration is what you want to use your precious energy on. Some people rejoice in the opportunity to make it a production. That choice is yours. Just remember that using your energy in negative ways saps the positive energy too. If you can focus your energy on positive coping you will regain more control.

Coming to terms with your illness does not mean you have to like it. It is acceptance, pure and simple. This does not make you a “walking disease”; you are a cognitive (thinking) human being who just happens to have this rare illness. You will continue to have feelings, and these feelings will get hurt. It is all part of being human. Waiting for treatment or for transportation, and being more dependent for certain activities of daily living (ADL’s) can be frustrating. Keeping a book handy or crossword / word puzzles, music, letter writing will let you feel you are not wasting your time. Some people take their computers with them. Work on using the time constructively (something you can control to an extent), and don’t allow yourself to feel that precious time is being taken from you. Be prepared for the waiting. I don’t go anywhere without a book or journal articles. A lot of people have these new fangled cell phones that do almost everything, including computer access (something I remain technologically challenged to do). The choices are endless, unless you choose to limit yourself.

When you find yourself waiting and waiting, anger and frustration can easily take over, but they don’t have to; it is your choice. I liken this to being stuck in traffic, especially if I am running late for an appointment. I have a choice: I will be late no matter what, but I can...
Combo-Infusion-Therapy

A Promising Treatment Protocol for Refractory Pemphigus Foliateous

by Kirsten R Bellur

After several misdiagnoses, I was eventually correctly diagnosed with a severe case of Pemphigus Foliateous (PF) in July, 1998. Over the next 5 years, I had unsuccessful results with the commonly used, so-called “steroid YO-YO diet.” Prednisone, Imuran®, and even CellCept® proved ineffective at a dose less than 1500 mg/day. I went thru that regime twice, and after every failed attempt, my dose of prednisone went higher and higher. My condition had become recalcitrant. At that point, I had almost given up the hope of ever reaching long-term durable clinical remission.

I knew there were newer and better treatments options available, but since they were very expensive, and mostly used off-label for Pemphigus Vulgaris (PV), I was aware it would be an uphill battle to get approval from my health insurance provider without support from a leading expert in the field of immuno-dermatology. I decided then to write a letter to M. Peter Marinkovich, M.D., at Stanford University, (09/11/03) and explained my difficult situation. He requested that I visit him right away, and explained my difficult situation. He is the patient who needs to take greater control of his/her own destiny.

We tried IgG infusions. At first, they appeared to work well; I stopped using CellCept® and had tapered prednisone to a very low dose. But then I had a re-flare. We scheduled another course of IV IgG, but my condition worsened -- IgG proved not to be an effective monotherapeutical treatment option for me.

After reading the very promising study done with rituximab in Cologne, Germany1, where one of the participants in the trial was a PF patient, we decided to schedule a 4 week course of rituximab following the protocol (375mg per sq.m of body surface area). Because of my past experience with tapering of CellCept®, we added a course of IV IgG (4 infusions 4 consecutive days and 1 infusion every 4th week over a period of 6 months (4 + 6, a total of 10 infusions) (2g/kg of body weight), beginning shortly after the last infusion of Rituximab. It seemed to make sense to combine Rituximab with IgG, since it is possible to boost the immune-system after you have reduced the B cells. The two treatments can act synergistically.

It is now 16 months since I had the last rituximab infusion and 4 months since I had my last IV IgG. My condition improved immediately when we started the rituximab infusions, and I have been – as of today (01/01/07) - symptom free for more than 14 months. My drug taper was done on a “fast-track”; therefore, the quality of my life has improved greatly, as I no longer have to endure the pronounced side-effects of prednisone and CellCept®.

I was very encouraged, when I read the recent article in the New England Journal of Medicine, entitled “Treatment of Pemphigus Vulgaris with Rituximab and Intravenous Immune Globulin”2. I was aware that the Combo-Infusion-Therapy had been used for severe conditions of Pemphigus Vulgaris, though it followed a different protocol than the one I underwent.

However, the most compelling reason for sharing my personal experience with the Combo-Infusion-Therapy is that, due to the simple statistics of illness prevalence, those patients afflicted with a condition other than PV are less the focus of attention, and therefore seldom included in any clinical trials. An unintentional but unfortunate result of this is that it becomes an even harder battle to get our health insurance providers to cover the cost of expensive treatments. I have tried to address that problem in the past, but the answer has always seemed to be: PF patients will get the same treatment as those with PV. Thus, for PF patients, without trials or case studies as evidence, it is extremely difficult to develop logical arguments in favor of getting the treatments approved.

It has been a struggle to get to where I am at today. I would never have been able to achieve it alone. Considerable credit must go to Dr. Marinkovich, who has patiently helped me fight my battles to get approval for the costly but effective Combo-Infusion-Therapy.

I hope that by briefly sharing my experience, I may in some way embolden other Pemphigus patients struggling with years of ineffective or under-effective drug therapies to consider pursuing this very promising combo protocol. I realize it will only become a “standard of care” if and when the usefulness of the protocol is known to more practicing dermatologists. But realistically, often times, when it comes to the treatment of rare diseases like Pemphigus, it is the patient who needs to take greater control of his/her own destiny.

References:


There was an informal meeting of the Pittsburgh, PA Support Group in February 2007. The meeting was held at the oncology center of a local hospital. As always, it was good to see how well people are doing and getting on with their lives in different ways. This meeting was especially special because the nurse who knew me from a hundred IVIg infusions at Allegheny General Hospital - and who diagnosed Gloria’s pemphigus in 2005 literally saving her life – was there. It was amazing to see Gloria and Nurse Denise together in such a laid back way. Lesson learned: One person can definitely make a difference!

There are no current plans for future meetings. If you are interested, please contact me and I will get back to you as soon as possible.

Terry Wolinsky McDonald, PhD
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Gloria’s Health Smart Recipe

¼ cup sunflower seed
¼ cup oatmeal
1 T flax seed
1 T Lecithin
1 T wheat germ
2 cups Soy Milk (Silk)
1-2 bananas

First put all dry ingredients in the blender and blend. Remove dry ingredients.
Put in 2 cups of Soy Milk plus banana and blend.
While blending, slowly add in dry ingredients. If you want to you can add a second banana.
...continued from LOSS OF CONTROL, page 7

arrive calm or an agitated nervous wreck. I find deep breathing and neck/shoulder relaxation exercises very easy to do in the car. Soft music can also help. Some people enjoy books on tape.

How you choose to live affects the quality of your own life, of course, but it also affects the quality of life of those closest to you. It is not always a matter of the glass being half empty or half full; sometimes it is just a glass with water in it. Some days will be better than others, and none of us, even with the same disease, have identical symptoms or pain thresholds. Remember that most people are afraid of change, even positive change. Changes can certainly be viewed as threatening, or they can be viewed as challenges and opportunities. The scenario is a matter of choice.

Positive growth will always come from working from your strengths. Identifying weaknesses and problem areas is important in creating goals, but you will need to identify your strengths (including any support systems) in order to achieve those goals. Your strengths (e.g., intelligence, persistence, support system, etc.) will aid in coping with anxiety, mood changes, the symptoms of the illness and negative medication side effects. With new coping skills, adaptations, and relaxation techniques (deep diaphragmatic breathing, imagery, etc.) you can break the cycle of a downward spiral and adapt to the ongoing and unpredictable changes you are facing in your life.

If you are not already in some kind of counseling or therapy, or even if you are, you can make up your own treatment plan*. You will need to make five columns. Identify at least three priority problem areas in your life. This will depend on your own symptoms and situation and also that of others in your life. In the second column, write down your long-term goals. In the third column, state measurable short term goals. For example, “I will make at least two positive self-statements every day” would be reasonable if you are having a lot of negative self-thoughts. If you are isolating yourself, “I will have social contact at least 3 days/week” may be reasonable for you. In the fourth column you will write how you plan to make positive progress toward your goals. Will psychotropic medications, or at least a psychiatric evaluation, be part of how you intend to reach your goal? Will you read certain books or use self-help workbooks to help you better understand cognitive distortions and cognitive psychology? (If you do choose a self-help workbook, the ones by David Burns are excellent and very understandable.) In the fifth column you will put an estimated date by which you hope to achieve the short term goals. Psychologists generally redo treatment plans every six months or more frequently. And, remember that these goals are not written in concrete. Your problem areas and goals may change by time and/or unex-
pected changes in your life. Having a plan that is reasonable and allows positive completion of the short term goals is helpful in giving you more control in your life. Once you successfully achieve a goal you can concentrate on the others, or you can add a new short term goal. Again, there are a lot of choices here.

Some areas which may be affected include: Increased stress levels; concentration problems; decreased self-esteem; increased worry and high anxiety, and feeling isolated and misunderstood. Some people close to you may complain that you complain all the time, while you are thinking “If they only knew the things I am keeping inside...”. These are probably the things to talk to a professional about- psychologist, licensed therapist, counselor, or spiritual counselor. There are always problems we feel we have put to rest long ago, but now they may be brought to the forefront. In therapy (usually in conjunction with an antidepressant or a combination of antidepressants prescribed by a family doctor or psychiatrist) you can freely talk, vent, cry, ask questions, or otherwise express feelings in a nonjudgmental and trusting environment with a professional who is LISTENING TO YOU. You will learn to pace yourself, rational (versus emotional of distorted thinking), how to live a proactive and fulfilling life, relaxation methods, and positive and personalized coping strategies. And, don’t forget to exercise – even if this just means stretching a couple of times a day or going up and down the steps a few times. You can do push-ups. You may start with one or two (on the knees for women), but you will be surprised at how quickly you will gain strength. You are not training for a marathon (At least most of us are not.), but you will want to try to not lose flexibility or strength even if you are not interested in gaining strength.

Coming to terms with your illness won’t happen overnight, but learning and using positive coping/relaxation techniques can be learned quickly and utilized often. Coming to terms with the uncertainty of life changes brought on by chronic illness will challenge you to be proactive and to use the cognitive skills all humans have. You will be more resilient regarding your treatment and in WAITING for doctors, tests, test results, hospital registrations, prescriptions, answers... Instead of getting perturbed by waiting for others, PLAN around the known and be ready for surprises. You may find you have a lot more control as you come to terms with your illness and yourself.●
The 2006 Patient/Doctor Meeting was a tremendous success. The following are some of the questions and answers from the meeting held September 16-17 at New York University’s College of Dentistry’s Saklad Auditorium in New York City.

Q. I have a high ELISA Dsg 3 score, but no disease activity? Is a titer test of ELISA test really indicative of disease activity?
A. It might that some antibodies might not be pathogenic. These tests can be useful though in measuring disease activity in some people.

Q. How do you manage a team of doctors?
A. It can be difficult. You need a good Internist to help “quarter-back” for you. Often with pemphigus/pemphigoid, the Dermatologist is the main physician. But, each physician taking care of you should know what others are doing.

Q. Permanency of long-term remission?
A. Over time, the vast majority of patients will go into remission for at least 10 years.

Q. Does PV always need systemic treatment?
A. Although every person is different, systemic treatments are almost always used. We know prior to 1950 mortality rate was 50% after 2 years, and 95% by 5 years. The earlier you intervene, the disease a better chance for remission. However, there are patients who have such mild disease (a small number) because the disease might be localized or very minor. As soon as expansion of disease, steroids should be given.

Q. How do you know the best way to treat the disease?
A. Must treat the disease aggressively from the beginning to try and get totally clearing. Some doctors like the use of steroid-sparing drugs to help get the disease under control and into remission faster.

Q. How often should patients be seen?
A. It needs to be tailored to individual. If a patient has severe disease, doctors might see a patient once a week. As a patient gets better, the visits would tend to be reduced. Although treatment protocols could drive the number of visits.

Q. If a patient is in remission should you continue to have a titer test?
A. It is important to just manage the disease. Generally speaking there is a correlation between disease activity and titer count. What is really important is whether there is evidence of the disease not whether there are antibodies present.

Q. If a patient is doing well on 5 mg of prednisone, at what stage do you continue to taper the medication?
A. There is a split in decision. Some believe that because pemphigus is a chronic disease, you should stay on a small dose forever. Some believe that it is possible to stop all medication. Each doctor has a different strategy, but it can be a personal decision depending on activity.

Q. Does bodyweight factor in to dose?
A. Yes. It is widely believed that dose should be 1 mg to 1 kilogram of body weight for both steroids and immunosuppressives.

Q. What is the mean age of the disease?
A. Mean age of pemphigus in Iran, Pakistan, and China, the average age is around 19. In the U.S., it is usually higher but it is being diagnosed in young adults.

Q. What should be the average time to diagnose the disease?
A. Because pemphigus lesions can look like other lesions, and it is rare, average diagnosis time is months, not weeks.
The following Q&A originated as an alert regarding a "phishing" scam posing as the US Social Security Administration. The actual SSA release can be viewed at http://www.ssa.gov/pressoffice/pr/colaPhishingScam-pr.htm.

Question: I'm a senior and got an email yesterday from the Social Security Administration that says if I don't respond by tomorrow, I'll stop receiving Social Security! Is this a scam? 

Answer: Yes, it's a scam. In November, the Social Security Administration issued a security alert about a new phishing scam aimed at seniors. 

The subject line of this supposed Social Security Administration email is: Cost-of-Living for 2007 update. The email claims its purpose is to inform Social Security recipients about the 3.3% Social Security benefit increase for 2007. It also contains the following statement: "NOTE: We now need you to update your personal information. If this is not completed by [a date close to today's date], we will be forced to suspend your account indefinitely."

The recipient is then directed to a bogus phishing website that is designed to look like the Social Security Administration’s website. At the phishing website, victims are asked to create a password and to confirm their identity by providing their Social Security number, credit card information and bank account information.

Action: Delete the email. **DO NOT** visit the website. Recognize that the Social Security Administration does not send out emails that require you to give out your personal information, nor do they use scare tactics and short deadlines via email to pressure you to update your account.

(Source: scambusters.com)

But what is phishing?

Computer hackers commonly replace letters with others to show they are “going against the system” such as replacing the letter “o” with zeros (e.g., d00d = dude) or “s” with “z” (e.g., codez = codes). That said, “phishing” is “fishing” for information. The term originated around 1996 when hackers were scamming America Online® customers out of their passwords and stealing their accounts. Phished accounts (hacked accounts) were traded among hackers as currency. Hackers would trade a dozen hacked AOL® accounts for some hacking software. These accounts were most commonly used for hosting illegal downloads like music, software, and games – three of the hackers most prized possessions.

Times have changed and the intent is no longer just for malicious fun. There are still chain letters out there asking for your money or assistance in settling a will or estate, but now criminals are going after big bucks and you are the target. Criminals have figured out that by creating websites that look like legitimate companies and banks people will provide almost any information requested of them.

As a rule of thumb **NO SITES, BANKS, OR COMPANIES** will ask for your account information…they already know it. If something is out of the norm then check it out. One way is to go directly to the website in question. **DO NOT USE ANY LINKS IN THE SUSPICIOUS EMAIL.** If it is from PayPal® then go to paypal.com. If it is from your bank go to your bank’s website. From there locate the Contact Us section and send them an email or call them to ask your questions.

Here are some sites I use to debunk or verify scams. **Snopes.com** is a good site to see about urban legends and scams (www.snopes.com). **Scambusters.org** is a watchdog group that helps Internet users avoid scams (www.scambusters.org). **PhishingInfo.org** is an informational site to educate Internet users on phishing scams and what to do if you think you have been scammed (www.phishinginfo.org).

If you have any questions about scams I recommend asking the legitimate site’s Customer Service department, researching it online, or emailing me at will@pemphigus.org.
Thank You to our 2006 Donors & Sponsors

The International Pemphigus & Pemphigoid Foundation would like to thank everyone for their support and contributions over the past year. Your help has been overwhelming and the Foundation would not be where we are today without your generosity.

The IPPF Growth Campaign was a huge success. Our generous PATHFINDERS matched donations dollar for dollar and together we raised over $65,000! This money will be used for research, support, and advocacy to help patients, caregivers, and families as we continue to search for a cure.

We cannot express how much we here at the Foundation are grateful for your support...THANK YOU!

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Our event planners are busy coordinating guest speakers, hotel discounts, entertainment, and dinner plans as they try and surpass the success of the 2006 meeting in New York! Don’t miss out! Registration forms and information will be included in the SUMMER 2007 issue of the Quarterly!

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