Medical Board welcomes Stanley

NPF Vice President in Charge of Scientific Affairs, Dr. Grant Anhalt, welcomed another noted scientist to the Medical Advisory Board. John R. Stanley has been at the University of Pennsylvania Medical Center in Philadelphia since 1995, where he is the Milton B. Hartzell Professor, and Chairman of the Department of Dermatology.

Dr. Stanley has made numerous important contributions to medical science both inside and outside of the bullous disease field. Most recently he developed the “knock-out Continued on page 14

The Hayden Report

This year they said would be different

By Cheryl Hayden

Lobovist, American Academy of Dermatology

In January, Congressional leaders of both political parties contended that the new millennium promised to bring an end to the gridlock that had tied the appropriations process in knots for the past few years.

The chairmen of the House and Senate Appropriations and Budget Committees promised quick work of both the budget resolution and the thirteen appropriations bills. For Republicans, it was felt that an early resolution of the 13 annual appropriations bills would provide the negotiating room they needed to do battle effectively with the President.

Democrats were also supportive, because an early adjournment might lead to more Republican concessions and would mean additional time to campaign for reelection. Neither will get their wish. The first stumble occurred this spring when Senate Majority Leader Trent Lott scuttled an emergency spending measure that would have provided funding for the troops in Kosovo and elsewhere, money for crop failures, and assistance for the victims of hurricanes and other natural disasters.

Senator Lott argued that the bill had become a “Christmas tree” and was filled with non-emergency spending. While Mr. Lott was right, his announcement was not expected. Congressional appropriators are still feeling the downstream effects of his decision, including continued rancor between the House and Senate Leadership.

Appropriations Chairman Bill Young has stated that the appropriations process is on track, but the level of acrimony during the debate on the Interior appropriations bill does not bode well for future cooperation between the two parties on appropriations.

In the Senate, Appropriations Chairman Ted Stevens has Continued on page 15

Alcatraz, in the foreground, is one of many popular attractions in San Francisco.

‘Summit in the City!’

San Francisco, open your Golden Gate!

Preparations for the third annual NPF Doctor/Patient Conference are nearing completion and excitement grows as the hour nears!

The slate of speakers presents some of the West Coast’s premier experts on pemphigus and pemphigoid, including Dr. Kari Connolly of UCSF, Dr. Sergai Grando of UC Davis, Dr. Francina Losada-Nur, of UCSF Dental School and Dr. David T. Woodley of USC.

Last minute reservations and queries about rooms should be directed to Janie Segall at 510-527-4970.

This promise to be just as informative and exciting as the first two conferences. More information is available on page three.

See you there!
If you want to see courage visit kids with pemphigus

This issue is dedicated to our children. Although pemphigus is mostly seen in adults, young kids and teenagers also find themselves with a diagnosis of pemphigus. As adults, most of us have the skills and knowledge it takes to deal with such a diagnosis, but kids don't. Imagine you are a young person, your life is new and your appearance is extremely important to you.

The five children we are focusing on are: Francesca, Jon Anthony, Racquel, Brandon, and Grey. They are the bravest young people I have ever met. Jon Anthony, Brandon, and Racquel have PV. Francesca and Grey are living with PF. At this time, Racquel is the only one presently in remission.

Francesca has had the disease the longest. She is a resident of the San Francisco Bay Area. When I first met her she was a child. Now she is 16, and is working in the community to help children with skin diseases. She is a fine young woman making a difference. Jon Anthony has one of the worst cases of pemphigus vulgaris ever seen by his specialists. Throughout his ordeal, he has had an amazing attitude. He has had many ups and downs; in and out of the hospital so many times, in and out of school as well. In spite of all that, he is a warm, friendly, inspiring young man. At the end of last year we presented his name to the “Make A Wish Foundation.” They were so taken with him and his story that they sent him and his family to Universal Studios in Orlando, so that he could have his special wish.

Then there is Grey. He is 5 year old now and has PF. In the last 2 years or so he has gone through so much for one so young. I’ve seen Grey twice in the last six months and he is an amazing child. He knows about his disease and he knows about the drugs he is taking. His mother makes sure he lives as normal a life as he possibly can. He is a very loving and caring little boy and loves to give hugs.

I met Racquel two years ago in New Orleans. She has lived through a lot over the years, dealing with classmates not understanding, the effects of high doses of prednisone, etc. She met these challenges with grace and charm, and is now free of disease. Brandon is another teenager dealing with PV. You can read about his remarkable contribution, and the stories of all the kids starting on page eight.

These kids all are very special. All the kids out there living with pemphigus are special, and we wanted to salute their courage and report how they are learning to live and deal with such a devastating disease in such a positive way. I believe that when kids get these diseases they gain special insights into life that we, as adults, don’t. Maybe it has something to do with having to meet this challenge without the baggage that most of us carry. Whatever it is, they have made and will continue to make this world a better place.

A correction: In the last issue of The Quarterly I said, “Almost all of the money we raise this year will go into a research fund...” What I should have said was that almost all money raised from special projects will go into a research fund. Since all of the money we raise is from donors, we still need to use some of the money for operating expenses.

Janet Segall
Executive Director

The National Pemphigus Foundation
“A common hope, an uncommon bond”

The National Pemphigus Foundation is a 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 people living with pemphigus or pemphigoid, their friends and families; to provide referrals to specialists; and to support research into advanced treatments and cures. Founded in 1994.

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Published Quarterly: Spring/February 15, Summer/May 15, Fall/August 15 and Winter/November 15.

The material presented in our journal is not intended as medical advice. Readers are urged to consult their physicians before making any changes in their health regimen. The opinions of contributors are not necessarily those of the NPF.

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THE NATIONAL PEMPHIGUS FOUNDATION PRESENTS

The Third Annual Doctor/Patient Conference

SUMMIT IN THE CITY
YOUR BRIDGE TO BETTER UNDERSTANDING

SATURDAY, SEPTEMBER 23, 2000
9:00 AM TO 5:00 PM
AT THE HOLIDAY INN AT THE WHARF
SAN FRANCISCO, CALIFORNIA

Join us in one of the world's favorite cities, San Francisco! This year's collection of doctors and patients offers every bit of the same kind of expertise and access enjoyed at the first two conferences.

Dr. Grant Anhalt will speak as will Dr. Sergio Grando from the University of California at Davis and Dr. Kari Connelly from the University of California at San Francisco. Additional speakers will be announced.

The conference includes breakfast, a dinner banquet, a full day of the latest news and information about pemphigus and pemphigoid and, of course, the highly popular Question and Answer session.

So come to 'the City,' see some sights, pick up some nuggets from the experts, meet old friends and make new ones. Don't miss this golden opportunity.

The focus is on treatment this time, don't miss your chance to ask your questions face to face!

$75.00
Attention please!!

Price includes breakfast and the dinner banquet on Saturday!

Confirmed speakers:

Dr. Grant Anhalt from Johns Hopkins University Medical School
Dr. Kari Connelly from University of California at San Francisco (UCSF), dermatologist and rheumatologist
Dr. Sergio Grando from University of California at Davis, researcher working on a non-steroid treatment for pemphigus
Dr. David T. Woodley from USC/Norris Comprehensive Cancer Center, Los Angeles, California, bullous disease and gene therapy
Dr. Francina Losada-Nur from UCSF Dental School

The National Pemphigus Foundation
P.O. Box 960, Berkeley, CA 94709-0606

Copy or cut out this form, check all that apply and return with payment to the NPF office before August 25. After this date, call the NPF office to make arrangements. Thank you.

☑ Yes, I would like to attend the Third Annual Doctor/Patient Conference in San Francisco, Saturday, September 23, 2000. There are ______ in my party.

Name: ____________________________
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ELISA as a sensitive and specific diagnostic tool for pemphigus

Scores may be useful to plan tapering schedules of corticosteroids and to predict flares or relapses

By Masayuki Amagai, M.D., Ph.D.
Department of Dermatology
Koto University School of Medicine
Tokyo, Japan

Patients with pemphigus have autoantibodies against epidermal cell-cell adhesion molecules, desmogleins. These autoantibodies inhibit the adhesive function of desmogleins and cause blisters and erosions on the skin and mucous membranes. Detection of these autoantibodies is required to make a diagnosis of pemphigus. The conventional and most-widely performed diagnostic test is indirect immunofluorescence staining using monkey esophagus or normal human skin as a substrate [1,2]. You prepare thinly-sliced sections of the skin or esophagus without fixation (fixation destroys the antibody binding sites or epitopes of desmogleins).

You incubate these sections with sera to be examined. If the sera contain antibodies against desmogleins, the antibodies bind to the desmogleins on the cell surface of keratinocyte in the section. You then incubate the section with fluorescence-labeled anti-human IgG antibodies. These second antibodies detect the anti-desmoglein antibodies bound on the section. You can see the fishnet-like pattern of fluorescence staining under fluorescence microscope (Fig. 1), which means positive for pemphigus autoantibodies.

The immunofluorescence staining is useful as a diagnostic tool for pemphigus, although it has several disadvantages. If sera contain anti-nuclear antibodies or anti-cytoplasmic antibodies, those antibodies stain the nucleus and cytoplasm and mask the staining of the cell surface, which leads to pseudo-negative reactivity. If sera contain antibodies against some component of cell membrane, those antibodies stain the cell surface of keratinocyte just as the pemphigus autoantibodies do, which lead to pseudo-positive reactivity. It is difficult to compare titers which are measured at different time points or by different facilities, because each section may contain different amount of antigens. Furthermore, it is almost impossible to differentiate pemphigus vulgaris (PV) and pemphigus foliaceus (PF) by this technique, because both sera show similar staining pattern.

One major advancement in this field is the availability of recombinant pemphigus antigens (desmoglein 1 or Dsg1 for PF antigen; desmoglein 3 or Dsg3 for PV antigen). These recombinant antigens (rDsg1 and rDsg3) were produced by cultured insect cells infected by recombinant baculovirus [3,4]. The rDsg1 and rDsg3 represent the epitopes of the native antigen. The column containing beads coupled with rDsg1 and rDsg3 was able to remove essentially all the pathogenic anti-Dsg1 and anti-Dsg3 autoantibodies from patients’ sera, respectively. Using rDsg1 and rDsg3 as an antigen source, an enzyme-linked immunosorbent assay (ELISA) was developed for detection of pemphigus autoantibodies [5,6]. rDsg1 and rDsg3 is coated on the bottom of a small cup (ELISA plate), and you incubate the plate with sera to be tested for one hour. If the serum contains pemphigus antibodies, the antibodies bind to the rDsg. You then incubate the plate with peroxidase-conjugated anti-human IgG antibodies, which bind to the pemphigus antibodies bound to the plate. Then you develop color which is related to the amount of peroxidase and thus indirectly to the amount of the pemphigus antibodies. The color change is quantified by an ELISA reader, which measures the absorbance. By using standard sera we can compare results from different plates, even when run on a different day under different ambient conditions, and even in different laboratories. The whole test takes less than 3 hours to obtain the results.

ELISA using rDsg1 is able to detect specific antibodies against Dsg1, and ELISA using rDsg3 is able to detect specific antibodies against Dsg3. Thus, by combining both ELISAs, we can make diagnosis of pemphigus and even tell the subtypes of pemphigus without clinical or histological information as follows [7]; if the serum is positive for Dsg1 and negative for Dsg3, it indicates diagnosis of PF; if the serum is negative for Dsg1 and positive for Dsg3, it indicates diagnosis of mucosal dominant type of PV; if the serum is positive for both Dsg1 and Dsg3, it indicates diagnosis of mucocutaneous type of PV. This serological diagnosis by ELISA is proved to be useful by many dermatologists not only in Japan, but also in USA and European countries.

Furthermore, these ELISAs are also useful to monitor the disease activity, because the ELISA scores showed parallel fluctuation with the disease activity along the time course. Therefore, ELISA scores may be useful to plan tapering schedules of corticosteroids and to predict flares or relapses by detecting increases in antibodies before clinical evidence of disease flares are noticed.

In summary, the Dsg1 and Dsg3 ELISAs using recombinant pemphigus antigens, when used together, provide a sensitive, specific and quantitative diagnostic tool for the detection of the pemphigus autoantibodies. These ELISAs should be used together with IIF test for the diagnosis and management of patients with pemphigus. The ELISA kits are available from Medical & Biological Laboratories Co. (MBL, www.mbl.co.jp/) or Rhigene Inc. (www.rhigene.com/).

Continued on page 13
Anhalt and Werth to supervise

Pemphigoid patients sought for new study

Alexion Pharmaceuticals, Inc., of New Haven, CT, has begun a small, pilot study of their monoclonal antibody, hSG1.1-mAb, in patients with bullous pemphigoid.

This study is being conducted at two hospitals - Johns Hopkins Hospital in Baltimore, under the supervision of Dr. Grant Anhalt, and the University of Pennsylvania Hospital in Philadelphia with Dr. Victoria Werth. Patient enrollment is scheduled to begin this month.

Bullous pemphigoid is a chronic, autoimmune disorder in which the immune system attacks the patient's skin, which in turn may cause extensive and striking blistering. A number of immune responses are involved, including the activation of complement proteins by antibodies.

Complement activation results in a one-way sequence of enzymatic and biochemical reactions known as the complement cascade. In this cascade, a specific complement protein, C5, forms two highly active, inflammatory by-products, C5a and C5b-9, which jointly attract and activate white blood cells. This, in turn, evokes a number of other inflammatory by-products, including injurious cytokines, inflammatory enzymes, and cell adhesion molecules. Together, these by-products can lead to the destruction of tissue seen in many inflammatory diseases.

Clinical research has demonstrated the presence of activated complement proteins in inflamed and involved skin, in patients with bullous pemphigoid. The monoclonal antibody, hSG1.1-mAb, has been shown to block the activation of the complement proteins at C5, which means that the normal, disease-preventing functions of complement are generally preserved (e.g., fighting an infection), while the production of the disease-producing actions of complement are blocked.

The main purpose of this trial is to discover whether or not the antibody is safe to administer to patients with bullous pemphigoid, and whether or not it actually blocks complement in these individuals. The antibody has already been given to patients suffering from systemic lupus erythematosus (SLE, or lupus), rheumatoid arthritis, and membranous kidney disease; the treatment has been very well tolerated, and has blocked complement in these people. In addition, we hope to discover if hSG1.1-mAb therapy will reduce the number of blisters associated with bullous pemphigoid, as well as the number of pre-blisters and swelling.

The study is randomized, blinded and placebo-controlled. This means that patients will be given either the antibody or placebo (salt water) according to a plan that assigns treatment in no particular order, and neither the patient nor the physician will know what the patient is receiving.

Patients will receive either the antibody or the placebo intravenously every week for five weeks, followed by every other week for two additional doses (four more weeks). The total amount of time that each patient will participate in the study is about four and a half months, including the pretreatment screening process and nine weeks of post-treatment monitoring (most of which will be done over the telephone).

Approximately 17 patients will be recruited, in the hope that 12 of them will complete the entire trial. Of these 12, nine will be randomly assigned to be given the antibody and three will receive placebo.

In order to participate in this study, patients will have to meet the following criteria:

- Must have a diagnosis of bullous pemphigoid, confirmed both by clinical findings (the type of blisters) and by a skin biopsy.
- Be 18 years of age, or older.
- Be not responding well to steroid treatment.
- Can not be taking dapsone, tetracycline, niacinamide, methotrexate, azathioprine, chlorambucil, cyclophosphamide or mycophenolate.
- Must be in reasonably good health, except for the bullous pemphigoid. For example, patients with liver disease, kidney disease, poorly controlled diabetes, recent serious infections or chronic or recurrent infections may not participate.
- Pregnant or nursing patients may not participate. Women who are younger than 55 years of age must agree to use a medically accepted form of birth control during the study period.

Prior to receiving any study medication, and before any blood tests or any other tests are performed, all of the details of the study will be explained to a consenting patient, and voluntary, informed consent will be signed. This study is being conducted in accordance with all federal and local laws. Patients may voluntarily withdraw from the study at any time.

There are a total of 11 visits involved, the first for screening, seven during which study medication is administered, and three follow-up visits: one at the physician's office and two by telephone. Information as regards the compound's safety will be collected by drawing blood samples for routine labs, as well as to determine the amount of study medication and complement activity in the patient's blood. Patient reports of any adverse events will be carefully recorded, and a physical examination and electrocardiogram (ECG) will be done before and after receiving the course of study medication. Efficacy will be evaluated by a dermatological exam along with photographs of the patient's skin and a small skin biopsy, all performed before and after the course of study medication.

Because hSG1.1-mAb blocks part of the complement cascade, there is the chance that a patient might be more susceptible to infections. Over 200 patients have been treated thus far, and an increased frequency of infections as yet has not been noted.

All antibodies, indeed all drugs, have the potential to cause an allergic reaction, and this is also true for hSG1.1-mAb.

If you would like to participate in this study, please speak to the physician who is currently treating your bullous pemphigoid. He or she can then call Dermatology Research at Johns Hopkins (410-955-7703) or at the University of Pennsylvania (215-662-6722) to discuss the details of the study. Please note, you would have to go to either Baltimore or Philadelphia once a week for at least two hours, to collect study information and receive an infusion.

Do not call either Alexion, or the National Pemphigus Foundation. We will only tell you to speak to your own physician.

If you are interested in learning more about complement and its role in disease, you are invited to log-on to the Alexion website at www.alexion.com.
Remissions in pemphigus

By Jean-Claude Bystryn, M.D.
Professor of Dermatology
Director of Immunofluorescence Laboratory
The Ronald O. Perelman Department of Dermatology
New York University Medical Center

Pemphigus vulgaris (PV) can enter into remissions in which all manifestations of the disease disappear and all therapy can be discontinued. How often, and when this occurs is unclear. Review of all major studies of PV conducted during the past 4 decades describes remissions as occurring in less than one-third of patients (1). However, a problem with these studies is that the incidence of remissions is usually provided at only a single time point. Thus, it is unclear how long it takes for remissions to appear, how long they last, and what happens when therapy is discontinued. Further complicating interpretations of the results is that the meaning of remission is often unclear. The criteria used by different investigators to define this event differ and/or are not provided. The practical outcome of this incomplete information is uncertainty about the management of pemphigus. It is unclear whether treatment simply suppresses the manifestations of the disease and must be continued permanently, or whether complete and durable remissions can be induced that permit therapy to be safely discontinued.

To answer these questions we examined the induction of remissions in 40 patients with pemphigus vulgaris who were followed for a prolonged period (on the average of 7.7 years) by the same investigator. The results of the study have recently been published in the Journal of the American Academy of Dermatology (2).

A strict set of entry criteria was used to include patients in the study, to minimize the effects of patient selection bias on the results. These included: a) diagnosis of PV confirmed by clinical, histologic, and immunofluorescence criteria; b) first seen shortly (<3 months) after the diagnosis of pemphigus, to exclude bias from early death; c) seen continuously by the same investigator during the course of their illness; and d) a minimum of two years of follow-up information from onset of disease. All patients were treated conventionally with steroids, with or without adjuvants, using guidelines that have previously been published (3). All patients were followed and evaluated using defined criteria for disease activity and remissions, to ensure a consistent evaluation of clinical outcome. Scores were recorded for the most severe phase of the disease during the first year of treatment, yearly on the anniversary of diagnosis, and at last follow-up. Complete remission was defined as a period greater than one month during which the patient was on no systemic therapy and lesion-free.

Partial remission was defined as a period greater than one month during which the patient was lesion-free and on no more than 15 mg/day of prednisone or its equivalent; or on only 100 mg/day or less of cyclophosphamide or azathioprine; or on only gold or dapsone. Duration of remission was classified as short if at least one month but less than 6 months, and as long if 6 months or longer. Time to partial or complete remission was calculated from date of diagnosis to onset of partial or complete remission.

The results show that pemphigus improved with time in almost all patients. Improvement was particularly rapid during the first two years of therapy, with the severity score declining 64% from an average of 5.3 during the most severe phase of the illness to 1.9 two years after diagnosis (see Figure 1). Severity continued to decline, albeit more slowly, during the ensuing years. Five years after diagnosis the average severity score was only 1.4, indicating the disease was inactive or treated with <15 mg/day of prednisone in most patients.

Remissions were found to be much more common than previously reported. This is probably because the incidence of remissions increases with age, and we studied patients for prolonged periods. Remissions that were complete and long-lasting (no evidence of disease and no systemic therapy for at least 6 months) occurred in 25%, 50% and 75% of patients 2, 5 and 10 years after diagnosis. These remissions were durable, lasting on the average over 4 years. Actual duration is probably longer, since most patients in remission were still in remission at last follow-up. The bulk of the remaining patients were in partial remissions or had mild disease controlled on 15 mg/day or less of Prednisone or with only an adjuvant (see Fig 1). The course of pemphigus in different patients as evidenced by induction of remissions and flare in disease activity was variable, but followed one of 4 patterns. In pattern 1, the disease responded rapidly to treatment, and went into a remission that was complete and long lasting. This occurred in 17% of the patients. There was no flare in disease activity when treatment was stopped. The average time to complete remission was 15 months and the remissions were maintained to last follow-up for an average of over 4 years. In pattern 2, seen in 37% of patients, response to therapy was slower and intermittent but complete and long-lasting remissions were also eventually induced in all patients. Pemphigus in these patients fluctuated between periods of partial or complete remissions of various length, which were punctuated by flares in disease activity as the intensity of therapy was decreased. Relapses were usually less severe than initial disease activity. With continued therapy, all patients eventually had long-lasting, complete remissions that persisted for longer than 6 months following termination of all systemic therapy. The average time to the first complete long-lasting
Remissions
Continued from the facing page

Remission was 35 months. In the third pattern, seen in 35% of patients, disease activity also fluctuated but no long-lasting complete remissions were induced during the course of this study. This may be because these patients were on average followed for a shorter period of time.

However, disease activity in most of these patients eventually became mild and could be controlled by low doses of Prednisone (15mg/day or less), or with only an adjuvant. There was no mortality in patients whose disease followed these three patterns. In pattern 4, seen in 10% of patients, the disease was resistant to therapy and never went into a remission of any type. Mortality in this small group was high, occurring in two of four patients.

Two factors were identified as predictive of the course of pemphigus. One was initial severity and extent of disease. Patients with mild or moderate disease at diagnosis were twice as likely to enter a long-lasting complete remission as those with severe disease. The other was early response to treatment. Patients who responded rapidly to treatment were over twice as likely to enter a long and complete remission as those with a slower response.

These results indicate that the outlook of pemphigus is more favorable than currently believed. The disease can be converted into an inactive state in the majority of patients. Most patients will eventually enter a complete and durable remission that permits systemic therapy to be safely discontinued without an exacerbation in disease severity. The remaining patients will usually have only mild disease controllable with low doses of Prednisone or an adjuvant. The practical implication of these observations is that the ultimate goal of treatment in pemphigus vulgaris is to discontinue all treatment.

References

Let’s go to Israel!

Dr. Sarah Brenner, a Medical Advisory Board member and noted pemphigus researcher from Israel, and Janet Segall are exploring the possibility of taking a group of NPF members and guests on a trip to Israel to meet Dr. Brenner and pemphigus patients there.

The trip is tentatively scheduled for September 2001. The more people interested, the less expensive it would be per person. If you are interested in discussing this further, contact Janet at the NPF office. See page two for contact information.

Pemphigoid, a complete discussion

By Edward Tenner M.D.


The article is by Kim B. Yancey, MD; Conleth A. Egan, MB, MRCP. After presenting a typical case of bullous pemphigoid in a 67 year old female, there is a complete discussion of the three major clinical forms of pemphigoid: bullous pemphigoid (BP), pemphigoid gestationis (PG), and mucous membrane pemphigoid (MMP) also known as cicatricial pemphigoid.

A concise table compared many features of these disorders. For instance, the prognosis in BP is a “chronic course marked by exacerbation and remission,” in PG there is resolution after child birth with likely recurrence in subsequent pregnancies; no long-term adverse effects on fetus, and in MMP “chronic course with potential irreversible scarring of mucosal surfaces.” The approximate annual incidence of BP is 7 cases per million, of PG 0.5 cases per million and of MMP one case per million. The article then goes through a very detailed review of the pathophysiology (what causes the disease) of these disorders. Where the epidermis meets the underlying dermis is where the action is in pemphigoid.

Various proteins act as strings and staples to hold these tissues together. When these proteins are damaged by attacking autoantibodies the attachments are severed and the layers can separate forming blisters. In pemphigoid the blisters form at a deeper level than pemphigus, which occurs only within the epidermis. Therefore the blisters in pemphigoid tend to be more tense, while the blisters in pemphigus tend to break easily. Blood from patients with pemphigoid has been found to have autoantibodies against specific proteins that hold the epidermis to its underlying basement membrane, which is attached to the underlying dermis. The antibodies are mainly of the IgG type. They bind to proteins (antigens) having names like bullous pemphigoid antigen 1 and bullous pemphigoid antigen 2. These autoantibodies can be used to make a diagnosis of pemphigoid and to determine the clinical type. They also are critical in the etiology of the disease. A figure shows the area in the skin where the autoantibodies bind. They are slightly different in the various clinical forms of pemphigoid.

As is the case for many autoimmune diseases, certain genetic markers on the surface of lymphocytes called class II major histocompatibility complex haplotypes (DRB1*0301) are more common than in the general population. These areas on the surface of lymphocytes combine with pieces of the bullous pemphigoid antigens and help initiate the autoimmune response.

The article concludes with a discussion of treatments. Topical and oral glucocorticoids like Prednisone are the mainstay of treatment, but with more extensive involvement, or in the more serious forms that cause scarring, immunosuppressing agents like azathioprine, mycophenolate mofetil, or cyclophosphamide need to be used. The authors then speculate on how learning more about the specific proteins attacked by the autoantibodies may lead to new and specific immunotherapies for autoimmune blistering diseases i.e. pemphigoid and pemphigus.
More and more children with pemphigus are coming to our attention. As tough as it is for adults to cope, imagine being a teen who is just beginning to explore the world, or a child who doesn’t have a clue what is happening. Here five remarkable kids tell their stories.

I could not hug or receive a hug from my parents

My name is Francesca Tenconi, and this is my story. In December 1995, at age 11, I was a competitive swimmer on a U.S. swim team, and on my way to achieving my junior national time as a breaststroker. I noticed little bites, resembling mosquito bites, on my back and chest. I kept going to the doctors, and received different creams and antibiotics. Over the course of time, I received several diagnoses, from dermatitis to an allergic reaction, but none of the treatments were working.

By April 1996 my condition had become quite severe. The little bites had grown into large blisters that were full of fluid. When they burst raw, crusty lesions would appear. We were getting ready to go on a cruise, and I asked the doctor if the sun would be a problem. She said ‘go and have fun.’ Needless to say, it was the worst thing I could have done. Two days into the cruise the lesions spread into my eyes and all over my body. I experienced terrible itching and a burning sensation that I didn’t have before. My clothes stuck to me and the sand from the beaches irritated my skin more.

When we returned home my parents demanded to see a specialist. He diagnosed me as ‘a classic case of impetigo’ and gave me several medications, including rifampin, which we later learned is proven to induce pemphigus. At this point I had lost 85% of my skin. I could not go to school, wear clothes or go outside. Three biopsies, six doctors and two hospitals later I was diagnosed with pemphigus foliaceus on May 10, 1996. At a visit to the doctors on May 10, 1996 we were told that I might not survive until Monday, because of the loss of electrolytes and a staph infection in the lesions.

I was put on 80 mg. of Prednisone daily. Because I had very little skin left, my daily routine consisted of two hour baths, followed by a mixture of ointment and antibiotics that covered my body.

Later I had to take sanitary baths, to remove the ointment and eliminate body fluids which had collected beneath the ointment, and start the regimen all over. These procedures continued for 3 months. Because of the massive doses of steroids, I gained 40 lbs. in a month. I could not wear clothes, and slept on saran wrap so as not to stick to the sheets. I missed the last 11 weeks of school and could not swim, but I was happy to be alive. The one thing I will always remember is that I could not hug or receive a hug from my parents because it hurt so much.

I am now 16 years old, and still battling the disease. I have tried many drug regimens, but I have never been completely clear or gone into a remission. I am currently on 10 mg. Prednisone, 15 mg. Methotrexate and undergoing IVlg treatment.

I just returned from Crosslake, Minnesota where I attended Teen Camp Discovery, a camp for children with skin diseases. Camp Discovery is a place for kids to meet other kids with skin diseases, and to forget about their deformities and just be a normal kid for a week. They keep us busy with activities such as horseback riding, canoeing, fishing, arts and crafts, and my favorite, water tubing.

My 16th birthday was May 29, 2000, and I had a big wish fulfilled. With the help of my parents, I founded “Children’s Skin Disease Foundation,” a nonprofit organization. Through my foundation I hope to raise money for medical research to improve treatments and work towards cures for this various diseases, support Camp Discovery, and raise public awareness that so much education and support is needed. I do not want other children to have to go through what I have.

On September 30th, 2000 “Children’s Skin Disease Foundation” will host our first rubber duck race at Waterworld U.S.A. in Sacramento, California. We ask people to sponsor a duck for $10.00, and all lucky sponsored ducks will race down the Lazy Lagoon to win fabulous prizes for their sponsor, including a chance to win $1,000,000. If you would like to sponsor a duck, offer a donation or seek more information about CSDF please call (925) 947-DUCK (3823).

Further information about the CSDF can be found at www.csdf.org or for the duck race www.sacramentoduckderby.com. This foundation has applied for a 501 (3)c. This Foundation is waiting for approval. Donation exemptions are retroactive.
Dear Janet,

This is Jon Anthony Palisi thanking you and the Pemphigus Foundation for asking Make-A-Wish to send me and my family to Universal Studios and Disney in December 1999.

You see, I wanted to ask Doc Brown to take me back before this very bad pemphigus hurt me and to find a cure, so that it would go away forever. He couldn't do that. We took lots of pictures and movies. There was so much to see and eat but I couldn't eat. My mouth had sores.

We saw Pooh, Tigger and Piglet. At night we saw the Parade of Lights.

At the Wishing Well I wished for Mommy to have another baby so that she wouldn't miss me.

At Universal Studios Danny and I went on the Back to the Future ride three times.

We talked to so many nice movie stars. We talked to Lauriel and Hardy, Ghost Busters, Xena and Hercules. We took photos with them too.

I want to thank Dr. Sciuibba because I love him with all my heart. He wants me to get better so much. Dr. Bernstein and Dr. Ahalt are helping me too. Everyone, made me happy because I don't want pemphigus anymore.

Love,

Jon Anthony Palisi

We saw Pooh, Tigger and Piglet

Jon Anthony's brother Danny writes: In my little brother's case, the ulcers had spread all over his body. His feet, palms of his hands, fingernails, scalp, nostrils, eyes, lips, ears, everywhere possible. He's been given plasmapheresis and treated with Prednolone or Prednisonolone, Imuran, and currently Cytocin. Nothing seems to be working and Jon Anthony has gotten thinner and weaker. Immunologists know what pemphigus does to the body but they don't understand why it does or how it happens.

Below: Brother Danny, Jon Anthony and sister Laura are joined by a Christopher Lloyd impersonator in front of the Back to the Future exhibit at Universal Studios in Florida. Mom (Lydia) and Dad (Jerry) were on hand to make the day complete.
Racquel never once complained of any pain

My daughter Racquel (McKinney) began suffering from PV June 3, 1996. This is a day I will always remember just as if it were the day she was born. At this time Racquel was a beautiful innocent seven year old girl with nothing on her mind but what would she play with next.

The first signs of her PV were in her eyes, but she was not diagnosed at this time. Her pediatrician initially thought she had pink eye and that is what she was treated for. After four days of treatment without improvement, we went back to the doctor. She referred us to an eye specialist who thought Racquel had a bug in her eye because of the way it was blistered. Well, needless to say, there was not a bug in her eye. We returned to the child eye specialist and he was baffled. At his office they poked and prodded her eyes, and still could not figure out what was wrong. Again we were given medication.

After about two months of seeing him, he decided to put her on a low dose of Prednisone due to inflammation in her eyes. Shortly after taking the Prednisone her eyes began to clear, but the doctor did not want to keep her on the Prednisone, because he still did not know what he was treating. By this time it was also time for school to start. This was the hardest time of her life you see, because she was in school and being called names like “red eyed monster,” and “the girl with bloody eyes.” It was soon after school started that Racquel began to have lesions in her mouth, along with a moose odor. We saw many doctors ranging from the pediatrician, immunologist and oncologist to pulmonologist.

It was the pulmonary doctor who finally recommend a bronchoscopy be done. Racquel never once complained of any pain during this entire six month period. By this time Racquel had lost weight, because she could not eat and she had begun to vomit blood. The bronchoscope revealed that she had lesions on her vocal cords, down to her esophagus. Even after this the doctors still had no idea what she had. Racquel continued to suffer until May 1997, when the doctors decided to do a biopsy of her lesions. This is when we found out what she had: pemphigus vulgaris. Of course we had no idea what it was; there was not much literature on this disease, and what we did find basically said she was going to die.

For an entire year before she was diagnosed, my daughter never cried. Now that we know what she has, how could I stop the crying long enough to help her understand? I had just gotten my computer, and barely knew how to use it, but I was able to find the National Pemphigus Foundation. This is when we as a family begin to better understand this disease.

Racquel has been lucky in a sense, because she had skin lesions only once and it was on her hand, but we were able to cover them while she was in school. Those scars have healed and we thank God every day for allowing those scars to disappear. My daughter is now a beautiful 11 year old living with PV. She has been on her share of Prednisone, both orally and infusion, and she has taken other medications as well. The Prednisone stole her childhood, and it is just now that she is beginning to enjoy her life. The past year and a half she has been medicated free and we continue to pray and hope that she is able to stay that way.

I'm sure I don't have to tell you how bad it can be

Dear Ms. Segall,

Unfortunately, in June of last year, I had to deal with the toughest ordeal of my life, which is pemphigus. I’m sure I don’t have to tell you how bad it can be, considering you have gone through the same pain as I have. One of the most fortunate things that happened during that time was that the Foundation was holding its annual conference in New York, where I live. You may remember me from the conference;

I was there with my mother.

I’m very grateful that I was able to meet people who have overcome this disease. There are times when I think it will never go away, but then I think about all the people that I have met, and if they can get over it, so can I. The conference was great because my mother and I were able to have doctors explain some of the more complicated points of pemphigus. Through the foundation we were able to find Dr. Joyce Rico who has been a great doctor.

At the conference you talked about how you need all the money you can get because this is a charitable organization. When I heard that, I knew I needed to do something to help the Foundation.

For my senior year in high school, I was elected President of the Key Club, which is a community service organization that also raises money for different charities. As their President, I wanted to raise money for the Pemphigus Foundation.

Therefore, I came up with the idea of a car wash. It would be $5 for teachers to get their car washed and all the money would go to the Foundation. We did it on May 20th and not only was it a great day, but the car wash was a great success. We raised $313 and some teachers gave us additional money after they saw the great job we were doing. That was really a great day because, in a way, I was able to pay you back for making me feel like I’m not the only one dealing with this illness. My parents wanted to show their gratitude as well so they gave $75. Enclosed are two checks equaling $388. I hope that this money will help the Foundation continue so that no one with pemphigus will ever feel alone.

Thank you for all the support you give to me and the many others with pemphigus.

Sincerely yours,
Brandon Arroyo
After a year we finally had a name, pemphigus foliaceus

Note: This is a letter Grey’s mother, Meredith Peterson, has been sending to a variety of people and places.

To whom it may concern,

Please accept the following letter on behalf of my three year old son, Grey Peterson. I never imagined that I would be composing a letter in regards to my child suffering from a chronic illness, but who does? I am willing to bet that most people who read this letter have never heard of what my child has. So not only does my son have a rare disease, he has an unpopular one. And unless I make it popular in awareness, he will fight for things that you and I can’t imagine going without. It is called pemphigus foliaceus. It is an autoimmune disease, where the body attacks its own skin. It typically affects adults in their 40s and 50s and above. So, for my three year old to have it shows that this disease does not discriminate.

It is imperative to bring about awareness of this rare disease to the medical community. In our own situation, Grey went undiagnosed for a year because doctors had no clue as to what he had. He just kept getting worse. Looking as if he were a burn victim.

We can’t go to a new building without him asking if this is a doctors office, or does he have to have blood work, or a biopsy. He now knows exactly what he has and how to pronounce it to all the people who stare and ask him what is on his face. We literally had to stop leaving the house. He knows the names of his medications and I think he understands that they help make him feel better. I’ve made everyone in the family and even friends taste what he has to take every morning to survive. And the taste is nothing short of vile. This is a lot for a three year old to handle. I just want him to be out doing what three year olds are supposed to be doing, playing and enjoying life.

Grey was diagnosed on August 16, 1999. I can tell you every last detail of that moment, but I won’t bore you with the details. Pemphigus foliaceus, after a year a year we finally had a name. We just didn’t like it. I must admit I was in shock for several weeks. I didn’t even know what the questions were, let alone the answers. My saving grace was a piece of paper handed to me in the doctor’s office. It was literature on the National Pemphigus Foundation. It was the first call that I made. And in less than five minutes I was called back. Janet Segall was on the other end and must have talked with me for close to an hour. She helped me ease my pain, let me know what to expect next and just listened. When I hung up the phone I realized just how important the Foundation is to people who are affected by this devastating and rare disease.

I have also come to realize that pemphigus foliaceus is a part of who my son is. And will play a rather large role throughout his life. My hope for Grey and others afflicted with pemphigus is that they will always have the support and guidance of the Foundation. My prayer for all is a cure!

Thank you for your consideration of such a worthy cause.

Sincerely,
Meredith Peterson

Grey Peterson, age three.

Resources for children with skin disease

The Society for Pediatric Dermatology
was established in 1975 and currently has a membership of over 500. It is the only national organization specifically dedicated to pediatric dermatology.

For information:
Patricia Fraser
Administrator
5422 North Bernard
Chicago, IL 60625
www.spdnet.org

Camp Discovery is sponsored by the American Academy of Dermatology. It is held at a number of locations, several times each year. At Camp Discovery children with serious skin diseases spend a week meeting others kids with serious skin diseases, while enjoying arts and crafts, swimming, fishing, boating and water skiing.

Dermatologists and nurse supervisors are on hand to offer support and advice, and many of the counselors have serious skin conditions themselves. “Fun, friendship, and independence are on the top of everyone’s agenda. And everyone shares in the discovery of what it’s like to be included,” says the AAD on their website at www.aad.org/Kids/index.html.

What could be better? How about free! And that includes transportation. The AAD picks up the tab through donations and other the assistance of other organizations.

For further information:
The American Academy of Dermatology
930 N. Meacham Road
Schaumburg, IL 60173
847-330-0230
888-462-DERM
Toronto group discusses CellCept

By Dan Goodwill
Chapter Leader

The Toronto support group held its Spring 2000 meeting on May 24 at the North Toronto Community Centre. A number of important issues were raised during the meeting.

There was much discussion of CellCept, an immunosuppressant drug that is being widely prescribed to PV patients in the Toronto area. Certainly there was consensus that the immunosuppressants, including Imuran, allow you to taper Prednisone treatments more quickly and, as a result, are valuable.

Two of the attendees mentioned that one of the side effects of CellCept is the feeling of tiredness. One PV patient indicated that he needs to take a nap in the morning and afternoon, directly as a result of the CellCept. Two patients highlighted the fact that weak ankles and tremors were a sign of a lack of potassium in their diets. This can offset through the intake of foods or supplements high in potassium.

For those patients with severe mouth and throat discomfort, the group agreed that fish with no sharp edges, milk shakes, “Ensure” (vanilla, not chocolate) and ice cream, are foods that are easy to eat and with considerable nutritional value, during periods of acute discomfort. There was also a discussion of the success that patients have had with Plasmapheresis. One patient currently taking this treatment mentioned that the protocol ends with a chemotherapy drug to prevent the antibodies from reoccurring. Only one patient had ever come back to take the Plasmapheresis treatments after the initial series of treatments. Overall, this treatment has been quite successful in the treatment of pemphigus.

The patient with the longest history of pemphigus in the group (5 years) talked about his recent flare after coming off all drugs. The flare was triggered by a bout with strep throat.

This led to a discussion of whether or not to have some sort of drug regimen after remission. One patient, who has been treated by Dr. Anhalt, mentioned that this doctor recommends a 5/0 prednisone treatment indefinitely. Dr. Anhalt believes this is good precautionary approach to protect oneself against a reoccurrence of PV.

Finally, the importance of a good family doctor was highlighted. It was agreed that this doctor can play a very valuable role in the treatment of the pemphigus patient, by bringing together the various medical disciplines that can come into play, due to the various side effects of the drugs.

Getting physical in Southern Cal

By Barbara Roller
Chapter Leader

The Southern California chapter met on Sunday, July 9 at Encino Hospital. We had a wonderful, very motivating guest speaker, Nancy Posnak. She is a Private Trainer for Spectrum Club and has been member Barbara Roller’s trainer this year.

Nancy spoke about the different aspects and benefits of exercise. A lively question and answer period followed.

Nancy also showed some of the members specific exercises that would help build muscle that has been lost as a side effect of medication. An important part of Nancy’s tall stressed weight training to stay strong! After our guest presentation, we had sharing & visiting. We had approximately 20 guests in attendance.

Our next meeting will be in October.
Major happenings in NY

By Matt Koenig

Over 30 people attended the latest meeting of the New York support group, held on June 1 at New York University in the Orentreich Conference room. With Jean Barish in attendance, new members were introduced, including one woman who had PV for over 25 years!

Joan DeLucie announced that she is stepping down as leader of the New York group, effective in September. Joan has done a superb job of both starting and leading the group for over five years ago. She was also instrumental in the highly successful Second Annual Conference held here last summer. Joan plans to travel and visit family on the west coast. We will all miss her but we are hoping she will stay in touch.

Dr. Joyce Rico gave a highly descriptive presentation on pemphigus in all its varieties. The group learned about the key cellular players that participate in the immune response, and the various alternative therapies that are available. One fascinating item concerned the behavior of white blood cells. It seems that most white cells aren’t constantly on the move through our bodies, scavenging for potentially dangerous invaders. Instead, they attach themselves to the walls of our circulatory system, waiting for chemical signals before going into action, like loungers at the poolside. One of the effects of Prednisone is to push these cells into circulation, like the life guard at a pool of lazy swimmers!

A golf outing Fund Raiser for the New York group is being planned for the afternoon of September 17 by Matt Koenig and Marcia Pepper, with the generous support of Norman and Linda Tafet (It’s their course). The new pitch and putt/mini course has just been completed in Flushing Meadows Park. Both the golf and lunch are available for $15 per pre-registered adult. Everyone is invited. Pre-registration by September 1 is absolutely necessary. For more information contact Matt at 516-825-4594 or mattkoe@aol.com.

...ELISA as a diagnostic tool

Continued from page four

References


THE ANHALT TAPE

A video lecture by Dr. Grant Anhalt of Johns Hopkins University on the current views surrounding the basic biology of pemphigus

Dr. Anhalt is Chairman of the Dermatology Department at Johns Hopkins University Medical Center in Baltimore, Maryland. He is NPF Vice President of Scientific Affairs and Chairman of the Medical Advisory Board. He is one of the world’s leading researchers into pemphigus. This illustrated material is not available in a similar format anywhere in the world.

- Professionally produced
- Available in VHS format only
- Approximately 60 minutes
- $100% of proceeds used to cover production costs and generate funds for additional NPF educational materials.

Suggested donation of only $150.00*

Please send me ______ copies(s) of Dr. Anhalt’s lecture and slide show.

Payment (Do not send cash): [ ]Check [ ]Visa [ ]Master Card

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Signature: ____________________________
Print name: __________________________
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City: __________________ State/Province: ______
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...welcome to John Stanley

Continued from page one

mouse", that allows researchers to raise mice which have one or another specific gene removed. This causes various medical conditions to arise in the mice which researchers can more easily study in the lab. With Dr. Masayuki Amanai of Keio University in Tokyo, Japan; another member of the NPF Medical Board, Dr. Stanley identified the nature of the pemphigus vulgaris and pemphigus foliaceus antigens. Later, on his own, he cloned the gene for the PV antigen.

“I am delighted to be a new member of the Medical Advisory Board of the National Pemphigus Foundation,” said Stanley. “This foundation has been incredibly supportive of our patients with pemphigus. Most importantly, through the Foundation patients can network with other patients and feel they are not alone in trying to cope with these difficult diseases. They can share their thoughts and feelings, as well as trade practical tips for dealing with the many intricacies of therapy and disease that we physicians may not appreciate.

“Of course, as physicians interested in pemphigus, we are delighted that the National Pemphigus Foundation joins with other skin disease patient advocacy groups to support research in pemphigus. My personal feeling and hope is that through such research this disease will be eliminated or become trivial in the future.

“Finally, I personally, am quite honored to be asked to serve on the Medical Advisory Board, and I am looking forward to many productive interactions with the Foundation.”

Dr. Stanley received his B.A., summa cum laude, in physics, from Cornell University; and his M.D. from Harvard Medical School. He then served as Resident and Chief Resident in dermatology at the New York University Medical Center. Subsequently, Dr. Stanley became a Visiting Scientist in the Dermatology Branch at the National Cancer Institute of the National Institutes of Health in Bethesda, Maryland. At the same time he held a joint appointment as Assistant Professor of Dermatology at New York University.

From 1981 to 1985, he was a faculty member in the Department of Dermatology Uniformed Services University of the Health Sciences where he was promoted to Professor of Dermatology in 1986. Dr. Stanley became a Senior Investigator in the Dermatology Branch, National Institutes of Health in Bethesda in 1985.

Dr. Stanley has received numerous awards and honors for his work, including the Outstanding Service Medal from the Uniformed Services University and the Superior Service Award from the U.S. Public Health Service.

Dr. Stanley was elected to the American Society for Clinical Investigation and the American Dermatological Association. Currently Dr. Stanley serves as an Associate Editor for the Journal of Investigative Dermatology and on the Editorial Board of the Archives of Dermatology. He is the author of over 90 scientific articles, scholarly reviews, and book chapters.

His major goals have been to understand the pathophysiology of these diseases and to determine what these diseases teach us about normal structure and function of skin.
...This year would be different

Continued from page one

Shepherded only two bills to the floor, although the committee has completed consideration of an additional five bills. In the past few years, the Senate has done marginally well moving appropriations bills to the floor, but seems to be having a harder time this year. This is fueled by intra- as well as inter-party animus.

Relations between Senator Stevens and his Majority Leader Trent Lott have never been very good, never fully recuperated from the events of this spring.

There is another element that may make this bad situation even worse - it is a presidential election year. Election year politics have already started to affect the conduct of business on Capitol Hill. While midterm Congressional elections are certainly sufficient to raise tempers and shorten fuses, the political infighting bred by presidential election politics is a whole other matter. Indeed, the fact that Governor Bush and Vice President Gore are polling so closely has increased temperatures to the boiling point in Washington.

Each party will be on high alert, hoping to take advantage of the others' missteps. Election year politics also takes its toll on the legislative calendar.

Members of Congress usually serve as delegates to their party's national conventions, and so the Congress is in adjournment during the Republican and Democratic conventions. This recess period, combined with an eagerness to adjourn the campaign, significantly reduces the possible days the Congress will be in session.

All is not bleak, however. There remains one government agency that enjoys strong support from both sides of the aisle - the National Institutes of Health (NIH). Two years ago the Congress embarked on a five-year plan to double the size of the NIH budget. In each of the previous two fiscal years, the NIH has received a 15% increase. It appears that the NIH may continue in this good fortune in fiscal year 2001.

The House bill, H.R. 4577, includes a $1 billion increase for the NIH in fiscal year 2001, increasing funding for the agency to $18.813 billion. This is a 5.6% increase; the same amount as the President's request.

The National Institute for Arthritis, Musculoskeletal and Skin Diseases (NIAMS) did proportionately very, very well on the House side, with an appropriation of $400,025 million, up from $349.5 million in the current fiscal year.

The House bill was passed after nearly a week of sometimes raucous debate, by the narrowest of margins, 217-214. Debate could have been even more furious, but efforts to attach legislative language to the appropriations bill that would have banned further research using human stem cells were thwarted.

H.R. 4577 does not fully fund many of the President's initiatives in education and worker training. The White House has indicated that unless these programs receive additional funding in conference, the President will veto the bill as written.

The Senate was even more generous to the NIH than their House counterparts. The Senate bill does provide for a $20.513 billion NIH budget, a $2.7 billion increase and 15% above the current fiscal year. The NIAMS did proportionately as well as the rest of the agency, receiving an increase of $51.7 million to bring it to a level of $401.161 million for fiscal year 2001.

In the past two years, the NIH has benefited greatly from the end-of-the-year haggling that has become the appropriations process. The biomedical advocacy community is working hard to ensure that fiscal year 2001 is equally bountiful.
Medications at reduced rates, or free

By Eileen Lucey

Depending on your needs and the attitude of your insurance company, finding the medication you need, at a cost you can afford, can be just one more source of stress.

Among the variety of complaints about modern HMOs and other managed care systems, is that they organize things to suit themselves and leave customers with fewer choices, or without any choice at all. People suffering from lesser-known ailments are particularly likely to encounter roadblocks.

While most pharmaceutical companies offer help to those in need, getting the information you require often depends on your doctor knowing the ropes. Just to begin, you must know which company manufactures your drugs, how to contact them and whether you meet the qualifications.

Nearly all companies require that your doctor make the initial contact. There are forms online to print and mail, or you can call to request the package.

Most of the companies on this list were found at www.rxassist.org. There also is a site specifically devoted to psychiatric drugs; those that are used for anxiety, depression and sleep disorders. The drugs available include Prozac, Paxil and Wellbutrin, and the site is www.nami.org/update/freemed.htm, the National Alliance for the Mentally Ill.

The U.S. Federal Poverty Guide applies in most cases, although some companies will make exceptions for higher income when offset by very high medical expenses.

Under the Federal guidelines, the poverty level for a single person is $8,350; for a couple is $11,250; for a family of three, $14,150; for a family of four, $17,050, etc. The amounts are slightly higher in Hawaii and higher still in Alaska.

To the right is contact information for companies providing the drugs most commonly used to treat bullous diseases.

Prednisone
SOLVAY PHARMACEUTICALS INC.
Patient Assistance Program
1-800-788-9277

CellCept
ROCHE PHARMACEUTICALS
Roche Medical Needs Program
1-800-285-4484

Imuran
FARO
Faro Patient Access Program
1-800-705-2630

Cytoksan
BRISTOL-MYERS SQUIBB COMPANY
Oncology/Immunology Access Program
1-800-272-4878

Cyclosporine
NOVARTIS PHARMACEUTICALS
1-800-257-3273

Methotrexate
IMMUNEX CORPORATION
Immune Reimbursement Patient Assistance Program
1-800-321-6449

Fusamaz
MERCK & COMPANY, INC.
The Merck Patient Assistance Program
1-800-994-2111

More information at www.pemphigus.org