Clinical trials are an important part of validating the effectiveness of new medications. We want to remind everyone about the ongoing clinical trials for pemphigus and pemphigoid. If the drugs you are now taking are not controlling your disease or are producing significant side effects, then contact your doctor about participating in available trials.

These drugs may assist in the treatment of the disease and may lessen or eliminate the need for ongoing prednisone therapy. In addition, they may have less short and long-term side effects than prednisone.

Here are a few questions you should ask yourself:

- Have I been able to reduce my steroid doses over reasonable period of time?
- Are the drugs I am taking now causing significant side effects?
- Is my quality of life being challenged?

All of the drugs that are now in clinical trial for pemphigus are drugs that have been approved by the FDA (Federal Drug Administration) for diseases other than pemphigus or pemphigoid.

Although most of the following trials are only available in the U.S., the **micofenolate mofetil (CellCept®)** trial for PV has been approved for study outside the U.S. in the following countries: Canada, UK, Turkey, India, Spain, Netherlands, Ukraine, Israel, Serbia, Germany, Switzerland, and Belgium.

CellCept is a drug that was developed for transplant patients as anti-rejection medication. It is considered a less problematic drug than other immunosuppressive drugs and has been effective in reducing steroid doses. Because of its favorable safety profile, CellCept is now being used off label in pemphigus and pemphigoid patients in many centers as the first choice of a steroid-sparing drug.

As with all immunosuppressive choices, because these drugs suppress the immune system, there are risks.

At Stanford University in Palo Alto, CA, there is an ongoing study of **Enbrel® (generic name etanercept)** for patients with PV. Enbrel was developed for use in people with Rheumatoid Arthritis. It has been on the market for over 10 years and is also approved for psoriasis.

How does it work? Your body makes a substance called tumor necrosis factor (TNF). In autoimmune diseases the body produces too much TNF. Enbrel blocks the action of TNF thereby reducing the amount of TNF in the body to normal levels. There are indications that TNF levels of patients with pemphigus are higher than normal. However, by reducing the TNF levels, Enbrel can also lower your ability to fight infections. The Enbrel study is looking for volunteers in California – preferably Northern California. They need about 5 more volunteers.

There have been reports that Enbrel is showing promise in treating mucous membrane pemphigoid (MMP). Although at the present time, there are no clinical trials for Enbrel and MMP,
A VIEW FROM THE TOP

2005: A VERY SUCCESSFUL YEAR

Welcome to the first issue of the Quarterly for 2006. In 2005 we expanded our focus to include more patients outside the U.S. We sponsored our 2nd International Scientific Meeting. We assisted more patients in understanding their options and empowering themselves. We helped save lives.

We all remember what it was like when we started presenting with lesions – how difficult it was because of the itching or the pain, and not knowing what was happening. Every day the IPF is contacted by someone newly diagnosed who is feeling that way. I can’t begin to tell you how many people have told us that our personal touch has made a huge difference.

Our work is more than answering e-mails or phone calls. We are educating members of the medical community to help them better treat patients. We are advocating for better healthcare and research with our affiliates through events like our first Capitol Hill Day. We are providing information on clinical trials that may bring us better treatment and better care.

The only way we can continue our work is with your support. Because we are a rare disease, we don’t have the notoriety that many organizations have. We are competing with other small disease foundations for public and private money. The best way for us to continue to live our mission statement is by asking our base to make sure we remain a viable organization.

There are many ways to help. If you own a business and you usually give your customers gifts during the holidays, donate to the IPF on their behalf. Sign-up for a matching gift program with your employer, or designate the IPF when you donate to the United Way. We are also taking vehicle donations, and when you shop online check out our shopping affiliation page - http://www.pemphigus.org/affiliates.html. You can order flowers, travel, or shop at WalMart online in the comfort of your home.

There are so many causes out there that are worthy of your support. We believe that people with pemphigus and pemphigoid are as important to the world as anyone else. We believe that your health and well-being matters too. We must continue to meet our goals and with your help we can.

IPF WISH LIST

The IPF is in need of a few itethat could help us further our efforts. Since we survive solely on donations we are asking if anyone has the following itethey can donate or to send a donation specifically for our wish list items.

Computer. We do all the graphics and layout for our publications. Our primary computer system lacks the processing power to perform as needed. We run Adobe In-Design, Illustrator, and Photoshop and are looking for a system with at least a 3GHz processor and 1Gb of memory.

Color Laser Printer. With rising printing costs we are looking at ways to reduce what we pay out to vendors. The IPF produces several flyers and brochures for events and the cost of one color laser printer is as much as one color printing job at a local copier.

CALL 916-922-1298 TO SUPPORT US!

The Pemphigus Quarterly
A publication of the International Pemphigus Foundation

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GREETINGS FROM THE PRESIDENT, IPF BOARD OF DIRECTORS

GROWTH CAMPAIGN UNDER WAY

This inaugural letter comes with great pleasure, passion, and gratitude for the opportunity you have entrusted to me to lead the IPF and work with such a talented group of dedicated individuals on our Board of Directors and our Medical Advisory Board, and a number of dedicated staff leaders and active volunteers within the Foundation. Your Board of Directors met in November 2005 and, with the help of a consultant, developed an exciting and challenging strategic plan for the Foundation that will ensure its growth as the agency that advocates for education, information, support, research and training for all those affected by, or involved in the treatment of, Pemphigus and Pemphigoid.

This Growth Campaign for the IPF will require the hard work of many people, and the generous contribution of time and money. At this very moment we are working with a handful of individuals – “path finders” - who are willing and able to make a significant commitment to the IPF Growth Campaign. We likewise plan to attract commitments from commercial entities to contribute to the campaign. And, we need every person who has been touched by pemphigus or pemphigoid to also make – in addition to whatever they have done already – an additional donation to the IPF.

With a solid plan in place, and the financial resources to drive the plan, we fully expect that within three years we will have an IPF that is better in advocating for its constituents and more influential in contributing to the generation of new knowledge in the optimal diagnosis and treatment of pemphigus and pemphigoid.

In future Newsletters I will provide updates to all of our constituents on the measurable progress we are making, and in doing so gain your continued confidence that your Board is performing well as a steward of your trust and support. Look for details on our progress in future communications in each of the following strategic plan initiatives: Patient Support; Public Awareness; Research; Education and Advocacy; Management and Operations; and Fundraising.

Please make a generous contribution to the IPF that is above your usual level of giving and please indicate your donation is to support the IPF Growth Campaign.

Sincerely yours,

David A. Sirois, D.M.D., Ph.D.
President, Board of Directors
International Pemphigus Foundation

Shop Online!
http://www.pemphigus.org/affiliates.html

The IPF now offers a shopper’s affiliation page on our site! We are looking into adding more merchants based on your feedback, feasibility, and program benefits for both you and the IPF. Merchants such as Amazon.com, WalMart, GiftBaskets.com, Easy Click Travel and others! We are excited to offer this service to you - services we all use, only now the IPF can receive a portion of your purchase towards our fundraising efforts.
check with your physician regarding the possible use of Enbrel for your disease. We would like to encourage all physicians involved in the care of MMP patients to consider developing a clinical trial for the use of Enbrel for MMP disease.

For Bullous Pemphigoid patients, there is currently a study at the Duke University using Rituxan® (generic rituximab). Rituxan is a drug developed for B-cell non-Hodgkin's lymphoma, a specific type of cancer cells of the lymphatic system. The lymphatic system includes lymph nodes and other organs that make immune and blood-forming elements for the body.

Rituxan works on the one molecule called CD-20. This clinical trial will help establish whether CD-20 plays a role in bullous pemphigoid disease. The drug is also showing promise in pemphigus vulgaris patients, but currently there are no ongoing clinical trials in the US.

The Rituxan study needs more BP volunteers.

At Duke University, NC; Univ. of PA, Philadelphia; Medical College of Wisconsin, Milwaukee; and Florida Academic Dermatology Centers, Miami a study using the drug Remicade® (infliximab), like Enbrel blocks TNF production. Enbrel is given as an injection, while Remicade is given IV.

Although all these drugs have potential serious side effects, for pemphigus and pemphigoid patients, they are considered less problematic than drugs such as Imuran (azathioprine) or Cytoxan (cyclophosphamide) which can severely depress immune function leading to a higher risk of infection and certain malignancies.

Many of you with PF are thinking, "What about us?" We want to stress the notion that although there are no clinical trials right now for PF patients, drugs in trial for PV would most likely be approved for patients with PF as well.

We must support these trials. Sometimes it is too scary to think about using something that is not approved for pemphigus or pemphigoid. But, as frightening as trying something new might be, the side effects of steroids over long-term can be more devastating. These drugs are not new drugs and have been previously used and tested. So, if you are unhappy with the way your treatment is progressing, ask your current physician to contact one of these centers for possible inclusion in one of these studies.

Check the IPF website http://www.pemphigus.org/trials.html for fur-
THE FIRST SUBCUTANEOUS IMMUNOGLOBULIN REPLACEMENT THERAPY APPROVED IN THE US
FDA APPROVES VIVAGLOBIN® FROM ZLB BEHRING

This product has not been tested or approved for use in pemphigus/ pemphigoid patients. This article is for informational purposes only.

ZLB Behring announced that the U.S. Food and Drug Administration (FDA) has granted marketing approval for Vivaglobin® (Immune Globulin Subcutaneous [Human]), an immunoglobulin (Ig) replacement therapy for treating patients with primary immunodeficiency (PI). Vivaglobin is the first and only FDA-approved subcutaneous (SC) Ig treatment, and can be safely self-administered by PI patients under a physician’s care in the United States. Vivaglobin is manufactured and marketed by ZLB Behring.

Vivaglobin delivers treatment directly under the skin (subcutaneously), offering a safe and effective alternative to intravenous infusions of immunoglobulin. Vivaglobin represents another treatment option for patients who may not easily tolerate the currently available intravenous method because they have poor venous access or experience serious side effects from that method. Vivaglobin also is appropriate for those who want the freedom and convenience of safe home self-administration of Ig replacement therapy.

“This milestone achievement means that thousands of patients with primary immunodeficiencies now have a brand new treatment option that was specifically designed to make their lives easier,” said Paul Perreault, Executive Vice President, Worldwide Commercial Operations. “ZLB Behring is dedicated to providing unique, innovative solutions that help save lives. Vivaglobin is a clear example of that commitment.”

PI is a usually-genetic group of disorders that compromise the immune system, leaving people vulnerable to often, life-threatening infections. An estimated 50,000 Americans have PI. Immunoglobulin is a life-sustaining blood product that has become standard immune replacement therapy for most people living with PI, and nearly 70 percent of PI patients receive Ig replacement therapy. Since the 1980s, the first-line therapy for most PI patients has been intravenous Immunoglobulin (IVIg), in which a pump delivers the immunoglobulin through a needle into the vein.

Experience shows IVIg to be an effective, safe, life-saving treatment. However, many patients may not easily tolerate intravenous infusions because they have poor venous access or they experience serious side effects. Vivaglobin allows patients to use a small, portable pump to self-administer their weekly subcutaneous infusions. With Vivaglobin administration, peak serum Ig levels are lower than those achieved with IMg. Subcutaneous administration results in relatively stable steady-state serum Ig levels when administered on a weekly basis. This serum Ig profile is representative of that seen in a normal population.

The FDA approved Vivaglobin on the basis of results of a pivotal open-label, prospective, multicenter clinical study conducted in the United States and Canada, evaluating the pharmacokinetics, efficacy, safety and tolerability of Vivaglobin in adult and pediatric subjects with PI. In this study, 65 adult and pediatric PI subjects previously treated monthly with IVIG were switched to weekly subcutaneous administrations of Vivaglobin for 12 months. Subjects received a weekly mean Vivaglobin dose of 158 mg/kg body weight which was 136% of their previous weekly-equivalent IVIg dose.

The annual rate of serious bacterial infections (defined as bacterial pneumonia, meningitis, sepsis, osteomyelitis, and visceral abscesses), the primary endpoint, was 0.04 infections per subject per year. Pneumonia was reported in two subjects. The annual rate of any infections, a secondary endpoint, was 4.4 infections per subject per year.

A 6-month, non-IND study of Vivaglobin was conducted in Europe and Brazil and generated safety and efficacy data similar to those reported in the clinical study conducted in the United States and Canada.

Vivaglobin was previously approved in a number of European countries and a...
...continued from VIVAGLOBIN, page 5

market application in Canada is currently under review.

Commercial preparations are underway to make Vivaglobin available to PI patients in the United States who desire this new treatment option.

PRIMARy IMMUNODEFICIENCIES

PIs are a group of usually-genetic disorders that cause a malfunction in part or all of the immune system, keeping the patient from fighting off infections caused by everyday germs. For individuals with PI – many of them children – infections may not improve with treatment as expected, and may keep returning. As a result, patients may face repeated rounds of antibiotics or be hospitalized for treatment. Repeated infections can lead to organ damage, which, over time, can become life-threatening. In some severe cases of PI, infections may result in a patient being hospitalized repeatedly. Some infections, such as meningitis, may even result in death.

Nearly 100 types of PIs exist. Most are inherited, but in some cases the cause is unknown. No single treatment works for all of the different types. Infusions of replacement antibodies (immunoglobulins or Ig) can help supplement the immune system to prevent infection in nearly three-quarters of those people living with PI whose disease is tied to an antibody deficiency.

For more information on PI, please visit www.zlbbehring.com or contact the leading PI patient advocate groups in the United States, the Immune Deficiency Foundation (www.primaryimmune.org) and the Jeffrey Modell Foundation (www.jmfworld.com).

IMPORTANT SAFETY INFORMATION

In clinical studies, Vivaglobin has been shown to be safe in both adults and children. As with any medication, side effects may accompany treatment.

The frequency of side effects was based on a review of more than 3,600 injections given during the clinical trial in the United States and Canada. The most frequently reported side effect was injection/infusion site reaction, which generally consisted of mild or moderate swelling, redness, and itching at the site of injection/infusion. In clinical trials, these reactions tended to decrease substantially after repeated use.

The most frequent adverse events reported by subjects irrespective of causality included headache, gastrointestinal disorder, fever, nausea, sore throat, rash, allergic reaction, pain, diarrhea and increased cough.

Because Vivaglobin is made from plasma, as are all commercial immunoglobulins, the risk of transmitting infectious agents, including viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, cannot be completely eliminated.

For more details and complete prescribing information on Vivaglobin, please visit www.vivaglobin.com, or call the ZLB Behring Medical Information Department at 1-800-504-5434.

A PATIENT SHARES HER RESEARCH AND CONCERNS REGARDING IVIG TREATMENT

IVIG CONCERNS OF A PATIENT

The views in this article represent those of the author.

By Kirsten R. Bellur

All patients receiving healthcare count on their medical professionals to make the best choices when it comes to their patient’s health – the cornerstone of the emblematic Hippocratic Oath. Therefore few of us ever verify or question their decisions – we implicitly expect that the best and safest products would always be preferred and used. I had, until very recently, been under the erroneous impression that all the IVIG products available on the market today were virtually the same in quality and safety – after all, the main component is human plasma – a natural product.

Medical News: Blood Contract is a Scandal. This headline in a Danish newspaper caught my attention.

When “something is rotten in Denmark” it is usually never “Much Ado about Nothing.”

Lars Heslet, the chef of staff / head physician, at the ICU (Rigshospitalet) the national hospital in Copenhagen, (largest hospital/medical research facility in Denmark) had refused to use the blood product, immunoglobulin, supplied by Amgros, the main supplier to all Danish hospitals of pharmaceuticals, a company they have a long-term contract with.

In a nutshell; Lars Heslet wants the pharmaceutical contractor to deliver a liquid version vs. a freeze-dried version of the product they have been getting, but as the company stands by their subcontractors, which translates into; they haven’t been able to accommodate his demand.

However, to secure the safety of the patients, Lars Heslet is at the present time... continued on page 8...
TWO DRUGS THAT MAY TRIGGER PEMPHIGUS “DISCOVERED”
SEARCH FOR THE GUILTY PARTY

by Prof. Sarah Brenner
Dept. of Dermatology, Sourasky Medical Center, Ichilov Hospital, Tel Aviv, Israel

When a 75 year old man was hospitalized with lesions on his back, right ear, chest, scalp and mouth, we set out to decipher its cause. Suspecting an outbreak of pemphigus triggered by a drug reaction in this man, we took a history and found he had a history of diabetes mellitus and hypertension for which he was being treated with glibenclamide and cilazapril, an ACE inhibitor. We know that pemphigus is an autoimmune disease whose onset and progression depend on an interaction between genetic predisposition and external factors such as drugs and diet. A survey of the medical literature turned up a number of reports on pemphigus developing after treatment with glibenclamide and cilazapril.

The next step was to confirm the diagnosis of pemphigus vulgaris. We did this histologic investigations and immuno-fluorescence studies on a biopsy specimen, which showed the typical findings of pemphigus.

We then used further laboratory studies to determine whether the glibenclamide (for diabetes) and cilazapril (for high blood pressure) were indeed the culprits. When a biopsied specimen from the intact skin of the patient was cultured with glibenclamide, we had our answer: suprabasal acantholysis - the histologic hallmark of pemphigus - was discovered in both these specimens. And, no signs of pemphigus were found in the normal unaffected skin of the patient or of a specimen from a healthy woman cultured without the drug.

The final definitive answer to our search - the connection between the glibenclamide and cilazapril and the patient’s skin eruption - came when we changed the patient’s medications and the lesions subsided and no new ones developed.

Not only did we solve the case in question, but we added two more drugs to the growing list of drugs that can trigger pemphigus. As a reminder, some drugs are referred to as “Potential Culprits” and “Probable Culprits” in the medical literature and their use is not always discontinued immediately when a drug eruption is suspected.

In France, the Association Pemphigus France is a newly formed support organization providing information and support for people living with pemphigus, their families, and caregivers. Please contact Peter Foldes: peterfoldes@tiscali.fr (01 47 32 42 05); Josée de Felice: felice@paris7.jussieu.fr (01 60 72 18 73), or Isabelle Gentile: ifgentile@free.fr (02 23 96 39 21)

In the UK, the PV Network is a patient support group providing information and support for people living with pemphigus, their families and caregivers. For information and support call 020-8690-6462 or send a self-addressed, stamped envelope to: PV Network Flat C, 26 St. Germans Rd., SE23 1RJ www.pemphigus.org.uk
receiving the liquid immunoglobulin from another supplier, until the issue can be resolved.

His reason for demanding the liquid immunoglobulin is, that because a stabilizer, sucrose, is added to the freeze-dried version, it can become life-threatening to critically ill patients. He maintains that according to some foreign studies there is an added risk to patients of renal failure when using the freeze-dried product, an increased risk he doesn't want patients exposed to.

Reference: Jyllands-Posten siden sidst...

The Danish newspaper article was a red flag disproving my assumption, which got me to thoroughly check out the IVIG product used by my health care provider.

To my surprise I found that the product they used contained 1.67g of sucrose, which is 5% - highest level of all brands. A lot of research and articles have been done on the topic IVIG/sucrose – therefore I am surprised that it is still being manufactured (accounting for 40% of the worldwide IVIG market) when it comes with an FDA warning that IVIGs containing sucrose as a stabilizing agent are associated with a disproportionate share of cases of renal failure.

To underscore this risk, here is a quote from the publication: “IVIG Induced Acute Renal Failure” by Mike Uyeki, M.D., UCLA Department of Medicine, published Sat. 01-Sep-2001:

“Between June 1985 and November 1998, 120 reports of renal adverse events following IVIG infusion have been reported worldwide. According to the latest MMWR updates, 88 cases have been reported in the US of which 90% (78/88) received IVIG that contained sucrose as the stabilizing agent.”

I would also like to point out, that in my secondary research, I came across well known hospitals that on the one hand supported sucrose-free IVIG with studies, but on the other hand accepted the other brands because of world-wide shortage; therefore according to them, their decisions would be based on availability and affordability at the time. I would not consider that good medicine – that is in my view, economics, and we in the decision sciences are still searching for a one-handed economist.

IVIG is used to treat many medical conditions and those patients often have other medical conditions and health risks to be taken into consideration. Since IVIG may be the best, safest and sometimes also last option after years of failed drug therapies, one would assume, logically that it would be evident that these patients should not be exposed to the added health risk from sucrose.

For example, Pemphigus patients who have been on Prednisone, Imuran, CellCept, Dapsone, Cytoxan, RituXan (used off-label), Enbrel (also in clinical trials currently) and/or other toxic drugs for an extended period of time are pre-disposed to among other health problems, steroid induced diabetes and renal failure. To counteract the adverse effects of long-term use of immunosuppressive drugs, many Pemphigus patients adhere to a recommended special diet, where sucrose is totally eliminated.

Considering the health risk, one would therefore prefer not to receive sucrose from IVIG infusions, but would like to see that a safer IVIG product would be considered.

I was encouraged that Dr. Lars Heslet has stepped forward and taken a firm stand against the pharmaceutical supplier, by deciding to use a safer non-sucrose-formulated IVIG product. And because of his effort, it has become the standard at all Danish hospitals.

Logically, with the patient’s health in jeopardy and from a pragmatic point of view – taking the additional risk of even more expensive-to-treat illnesses is almost certainly not cost-effective in the long run.

I am aware that most likely our practicing dermatologists do not have a say as to what IVIG product is used, because many do not offer the treatment in-house. As in my case the order was provided by an outside the plan provider, but had to be done, according to policy of my insurance company, at their own local infusion center, where my primary care physician/rheumatologist is in charge. Even he was unaware of the IVIG product used as the selection was done by the purchasing pharmacist for the whole area.

Actually, nobody here had given any thought to the quality of the product used. Therefore, after reading the Danish article and reviewing the literature, I decided to write a letter and request them to consider using a different sucrose-free brand.

My letter was reviewed by a panel of physicians and the purchasing pharmacist. They found my request reasonable, and checked into alternative brands. I was soon thereafter informed that from then on they would only use a sucrose-free product.

I wanted to share this experience with other Pemphigus patients, so that they would be better informed, and be able to question the IVIG product used. In order to improve the quality of our lives, we, the consumers of health care, need to be better educated and not take things for granted. Unfortunately as many of us know the hard way, time is not on our side, with every relapse the disease becomes recalcitrant and refractory to therapies. It is therefore of utmost importance for patients to take a pro-active approach to their treatments.

Kirsten Bellur holds undergraduate degrees in Economics and Social-Psychology & Demography. She did both her graduate and post graduate work in Decisions Sciences/Demography as well as her fellowship in the Population Research Lab at Kansas State University. She conducts private research on her own.
HAPPY 85TH BIRTHDAY

MARVIN ROSEN GARTEN

With all our love,
Karen, Michael, and Dana

and in memory of Cynthia & Bob Rosenthal

The IPF thanks you for the generous donations on your behalf.

HAPPY 75TH BIRTHDAY

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