



A COMMON HOPE,
AN UNCOMMON BOND

the Quarterly

SPRING 2005 • ISSUE #40

IPF WELCOMES NEW MEMBERS TO BOARD OF DIRECTORS AND HQ STAFF

Supplements and YOU

Thinking of taking Echinacea or Aphanizomenon flos-aquae? If so, you should read this.

See page 3

Rituximab

What is it, how it works, and some side effects explained by a doctor and a patient.

See page 13

IN THIS ISSUE

- 2 The View from Here
- 3 News You Can Use
- 4 Support Group News
- 5 2004 Annual Meeting Q&A
- 6 My PF Story: Jack Persad
- 7 Dr. Anhalt on Autoimmunity
- 8 IPF Joins Capitol Hill Day
- 10 Pemphigus 2005 Meeting in June
- 11 Aquatic Classes Can Soothe Aches
- 13 Rituximab Explained
- 14 2004 IPF Donor List

The IPF warmly welcomes three new members to our team. Michelle Domb-Hershberg and J. Gregory Wright join our Board of Directors while Will Zrnchik joins our office staff.

Michelle Domb-Hershberg lives in Lawrence, New York, with her husband, Sam and two children, Adam (11) and Sara (8). Michelle was diagnosed with pemphigus vulgaris at the age of 15. She graduated from New York University and spent one year abroad in Israel studying at Bar Ilan University in Ramat Gan.

Michelle is one of the owners of the Empire Hotel Group in New York City. She currently serves on the executive board for her children's school and is greatly involved in many non-profit organizations, both in the U.S. and overseas. Both she and her husband are very dedicated in helping the IPF in any way needed. Michelle and her family plan to move to Miami, Florida in the summer of 2005.

J. Gregory Wright, MBA, is a sales/marketing professional with substantial leadership and medical start-up experience. He has successfully launched three biotech therapeutic agents with different start-up organizations.

Gregory currently is the Western Regional Sales Manager for Medi-

cal Education Technologies, Inc, which manufactures and sells Human Patient Simulators (aka "Smart Dummies") that save lives by providing a learning platform that allows doctors, nurses, first responders, military medics and students to practice without harming real patients.



Greg Wright,
Rancho Cucamonga, CA

In his leadership roles, Gregory has served as the President and Board Member of the Laing's First Edition Ontario Center Homeowner's Association. As a business consultant, Gregory has also served as an Advisory Board Member of KanDu Resource Management, Pacific Alliance Media Group & GG Media, Inc. His interests are in strategic planning, organizational development, team building, project execution and marketing.

Experience, drive and abilities are complemented by a MBA in Business and Management from Pepperdine University and a BS in Biology from the University of Pittsburgh.

William J. Zrnchik II was recently appointed as the Director of Communications for the IPF. He comes to us from northwest Indiana where he was Sales/Project Manager for Air-Tite Insulation & Safe Guard Environmental Services. He served in the US Air Force's Security Forces from 1988-2002 where he took part in several military operations. He is



Will Zrnchik,
Albany, CA

Continued on page 6...



Janet Segall,
Director of
Patient Support, IPF

THE VIEW FROM HERE

A SUCCESSFUL 2004 BRINGS HOPE FOR 2005

The Board of Directors and the IPF staff would like to thank all of the people who donated both time and financial support to the IPF in 2004. Our future depends on the generosity of others. This past year our achievements grew. We had a very successful Annual Meeting and 10th Anniversary Celebration. We have our *Introduction to Pemphigus* booklet in Spanish. We welcomed two new Board members, **Michelle Domb-Hershberg**, and **Greg Wright**. And, we now have a new Director of Communications, **Will Zrnchik**. Will has been working

with me now since the beginning of November as a part-time, temporary employee. Because of his skills and enthusiastic attitude, we are very pleased to have him as a permanent part of our team.

Because of Will's skills, we have a better working database and a more interactive website. We have added several new features to the website. There is a Site Search. In our **Contact Us** section, you can send us comments, suggestions, and ask us questions online. Under **Patient Support** you can tell us your story and read some of the wonderful stories already posted. We believe you are **"more than your disease."** What are your hopes, your accomplishments, your successes? Your story

can give others hope and inspiration.

We are also planning our first **Capitol Hill Day** to be held in conjunction with our **8th Annual Meeting** (see page 8). The IPF will again be joining the American Academy of Dermatology (AAD) this year for their Capitol Hill Day in April where we will be asking Congress to recognize the need for research in skin diseases. There are many other problems that people with rare diseases face and we need to let our representative hear our voices. I look forward to seeing you there. •

Correction: Quarterly (Winter 2005, #39) should have been titled "Winter 2004."

International Pemphigus Foundation is a 501(c)(3) nonprofit organization. Our goals are to increase awareness of pemphigus and pemphigoid among the public and the medical community; to provide information and emotional support to pemphigus or pemphigoid patients and caregivers; to provide referrals to specialists; and to support research into advanced treatments and a cure.

Founded in 1994.

The *Quarterly* is published: Spring, Summer, Fall and Winter. 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 contents of the *Quarterly* cannot be reproduced or copied without written permission of the International Pemphigus Foundation. The opinions of contributors are not necessarily those of the International Pemphigus Foundation.

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JOINT VENTURE HOPES TO INCREASE FUNDING FOR PATIENTS AND RESEARCH PROJECT TO STUDY BULLOUS DISEASES

Congressional report language for the NIH FY 2002 appropriations bill requested that the NIAMS assess the burden of skin disease in collaboration with other Federal agencies and voluntary health and professional organizations. In response, the NIAMS assembled a committee, consisting of academia, voluntary health organizations, the NIH community, and other Federal agencies.

The AAD and the SID have joined together to oversee a technical panel on a Burden of Skin Disease Project. This joint program will measure social, emotional and economic cost of skin disease in the U.S. Bullous diseases (which include pemphigus and pemphigoid) are among the category of diseases selected to be a part of the study.

AAD President, Boni E. Elewski, M.D. said, "Cooperatively, these two groups have launched an initiative that will vastly improve our ability to both understand the scope of these diseases in the U.S. and to better advocate

on behalf of the patients who suffer from them."

Dr. Henry W. Lim, the Academy's representative to the Panel stated, "Bullous diseases are not all that common compared to acne..." On the other hand, bullous diseases are the ones that have a significant impact on the patients because the patient can be quite severely affected by a particular disease, which may also have significant costs associated with it.

The Panel hopes to have their report finished in time for the AAD's Annual Meeting in February 2005 that will be held in New Orleans (the IPF will be represented at the AAD meeting). The report will be used to advocate for support of patient and more skin disease research funding. •

Source: Dermatology World, An official publication of the AAD – Volume 14, Number 10, October 2004

IS THERE A RISK IN TAKING HERBAL SUPPLEMENTS?

HERBAL MEDICATION CAN HAVE ADVERSE SIDE EFFECTS

by Victoria P. Werth, M.D.

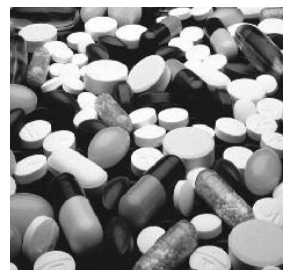


Herbal supplements are used widely, and some of these supplements may stimulate the immune system in ways that could be harmful for people who have or are prone to autoimmune diseases.

There are a number of herbal medications that have been studied and have immunostimulatory effects. Among these are Echinacea, the algae *Spirulina platensis* and *Aphanizomenon flos-aquae*. We recently reported three patients with autoimmune disease, two of whom had pemphigus vulgaris, whose disease exacerbated shortly after beginning one of these herbal medications (Lee and Werth, Arch Dermatol 140:723, 2004). In one case of dermatomyositis, the pa-

tient re-flared several months later after rechallenging herself with the same herbal product.

These herbs seem to affect the immune system by increasing pro-inflammatory proteins produced by inflammatory cells, and their effects have been studied in a number of experimental models. Studying the potential mechanisms and effects of these herbs in humans has been done in only a few studies, and much more work will be needed in order to document their potential toxicity in patients with autoimmune diseases. Until these studies are performed, it would be prudent for patients with pemphigus vulgaris to avoid potentially immunostimulatory herbal medications. •



TWO KIDS CAMPS IN 2005!

June 19-25: Camp Wonder, Livermore CA

July 31-Aug 5: Victory Junction Gang Camp,
Randleman NC

NEW! 2005 FAMILY WEEKEND!

October 7-10: The Painted Turtle, Lake Hughes CA

Camp Wonder
sponsored by
Children's Skin Disease Foundation

For more information, log onto CSDF's website at www.csdf.org and click on "Camp Wonder."

For one week these children can forget their disease and have fun!

IVIG, PERSONAL STORIES, AND DNA BRACELETS TOPICS OF DISCUSSION

SF BAY AREA SUPPORT GROUP MEETS

On January 29, 2005 members from the San Francisco Bay Area support group and Sacramento Support Group met in Davis, California at **Dr. Sergei Grando's** lab. We had a very enthusiastic crowd of around 40 people. Dr. Grando gave a presentation about his views on pemphigus research, and specifically on IVIg treatment. There was a lively discussion as to the pros and cons of IVIg.

We were very fortunate to have **Milo Careaga** talk to the group about the undeniable success he has had with the use of Rituximab (*see related information on page 15*). Milo has tried every drug on and off label for pemphigus vulgaris, and Rituximab seems to be the best one so far. Milo, who was diagnosed with PV ten years ago when he was 19, has decided to pursue a career in the medical research field. Milo's story of courage is very inspiring.



Milo tells listeners about his Rituximab experience



Amy tells attendees about the bracelets

Amy Granat spoke to the group about helping the Foundation's fund raising efforts by selling bracelets in the form of DNA. They will be available for sale in the Spring 2005. Created by renowned artist Carolyn Forsman, the bracelets will be available in two sizes. Petite sized bracelets, perfect for children and adults with slim wrists, will be in silver or rainbow. Regular sized bracelets will be in silver, rainbow, or hematite. Where and how to purchase these stunning bracelets will be announced on the IPF website.

Sonia Tramel, Interim Board President, and **Janet**

Segall, Director of Patient Support were also on hand. Dr. Grando generously provided everyone with a lunch of sandwiches, chips, and drinks and we are very grateful for his participation with the group. •



Created by Carolyn Forsman, the Springy DNA bracelet is representative of the DNA molecule that was discovered by Watson & Crick 50 years ago. Fashioned from spring steel, the bracelets are available in two sizes, petite and regular. Bracelets will be available in Spring 2005.



Attendees enjoy a light lunch while learning a little more about IVIg, Rituximab, and IPF fund raising efforts.

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www.idi.it/amb/csmba/index.htm

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Online/Website

www.pemphigus.org/support.html

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

THERE WAS A LOT TO BE ASKED AT THE 7TH ANNUAL PATIENT/DOCTOR MEETING IN LAS VEGAS

QUESTIONS & ANSWERS FROM IPF ANNUAL MEETING

These questions were raised at the International Pemphigus Foundation's 7th Annual Patient/Doctor Meeting in Las Vegas. Answers were given by the Doctor Panel. This is part one of a two-part article.

Q. As a new patient, can you give us an overview of the differences between pemphigus vulgaris and pemphigus foliaceus?

A. PV almost always starts with lesions in the mouth, and later on some will develop skin lesions. The opposite is true with PF. Lesions will appear first on the head, neck area and the shoulders. Oral lesions are never found.

Q. Is there a definition of remission that is agreed upon by all doctors?

A. We have been always been very concerned about what words mean, and unfortunately, there is no consensus as to what remission means. It can range from what people call complete remission - no evidence of disease and not being on any therapy, to good control - where an individual would be on small amounts of drugs, but no lesion; to some control when there are drugs and some activity.

Q. Defining the words doesn't really mean anything to me. I have to live with this disease.

A. Although this might not have

an impact on you directly, it is important to us who work on the disease so we can help you. For example - when comparing drugs we need to be able to define remission.

Q. Is it common for there to be a mis-diagnosis?

A. Diagnosis is based on three different things: What the disease looks like, the biopsy, and the titer tests. To the untrained eye, the disease could look like several diseases.



Q. Can we donate blood to the Red Cross?

A. You cannot donate blood. When you suffering from a disease, they do not want you to donate blood. No one is really sure exactly how antibodies work. They do not want to take the chance that someone with the right gene might get the disease.

Q. What percentage of patients get off all medications?

A. In one study 40 patients were followed. After 10 years 75% had no evidence of disease and were on no medication. 35% had partial remission where they had no sign of disease but were on a small dose of drugs - 15 mg or less of prednisone.

Q. For how long will a complete remission last?

A. Sometimes it can be for years, it is considered a remission if it is for 6 months.

Q. I am looking for a clear method of tapering. Do you decrease with no blisters or just some?

A. With BP, the risk of recurrence is less than pemphigus. BP is usually easier to treat, and everyone is different in terms of tapering. Don't taper if you are breaking out with new lesions.

Q. I am on prednisone, CellCept, Imuran and now I'm starting IVIg. The prednisone is being tapered, but when can I start tapering the other drugs so I don't have to be on so many different one?

A. If one medication doesn't work, then we try another until something does. CellCept and Imuran should not be used together. The drugs when used together are antagonistic. That information was established in

Continued on page 10

"I WAS UNCONSCIOUS FOR 13 DAYS. THANK GOD, I CAME BACK"

JACK HAS HAD A DIFFICULT TIME WITH HIS PF

Content Advisory: Some of the personal stories published by the *Quarterly* may contain graphic depictions that may be unsuitable for young readers or persons not familiar with the disease's effects.

by Jack Persad

I first noticed blisters on the back of my right shoulder in 1993 and thought they would go away. As the weeks passed, the blisters got worse and spread. I was seen by a local doctor who treated me with antibiotics. After a month the blisters spread even more. My doctor referred me to a dermatologist who gave me shots of more antibiotics - and even took blood to test for herpes.

By now, my entire back was covered with blisters. Finally, a biopsy was sent to Emory Hospital and only then my dermatologist determined that I had pemphigus foliaceus. He explained what PF was, and what the treatment to control the disease was. He said the condition is a chronic disease and the treatment to control it has very bad side effects. Being a healthy strong man of 45 at that time, the news I got from my doctor made me cry. It was about the worst thing I could imagine.

After months of treatment with Prednisone and Dapsone, the blisters were still spreading and now covered my entire body. I was referred to Dr. Robert Swerlick at Emory University Medical Center. Dr. Swerlick treated me for about 2 ½ years. The cost was getting me down, so I decided to go to the VA Hospital in Deator, GA.

In February of 1987, I had a very bad breakout and was admitted to the VA Hospital where they kept me for 28 days. I was first treated with 100 mg of Prednisone to control the PF. Once under control, I had a bone density

scan and it showed I had a bone loss of 25%.

I was treated with Prednisone and Imuran which I tolerated well, but I still had blisters. Imuran was stopped and I was then treated with CellCept. I had a bad reaction to the CellCept. The doctors then prescribed Cytoxan. I had a bad reaction to that also. I was then treated with a Rituxan I.V. drip which also did not work.

I then got very sick and was admitted to the VA's ICU and was treated for pneumonia and sepsis - my lungs had collapsed. I was unconscious for 13 days. Thank God, I came back. The doctors informed my wife my chance of survival was 40%. You can imagine how she felt when I was finally released from the hospital. I had lost almost 40 lbs and was unable to stand or walk for almost a week.

I believe that diet and exercise play a very important roll in controlling this disease. I now have this problem for almost 14 years and it has been hell dealing with and controlling it. I have tried almost all the medicines available - even IVIg.

Some of the foods that aggravate my condition are: fruits, potatoes, cabbage, nuts, tomato, curry, fried foods, milk and milk products, peanut butter, hot sauce, plantain, avocado, tuna in the can, onions, garlic, and coffee. I know it seems like a lot I cannot eat, but, for me the sacrifice has to be made to help the condition.

You can contact me at 404-767-0796. •

Continued from MEMBERS, pg 1...

the recipient of the Air Force's Meritorious Service Medal, Commendation Medal, Achievement Medal, and Outstanding Unit Award (with Valor). In 2000, Will was named his organization's Noncommissioned Officer of the Year.

His previous communication experience as Security Forces Network and Systems Manager capitalized on his meticulous and analytical approach to the situation. Will authored his organization's first-ever 5-year IT plan. This document was the foundation for his computer systems budget forecast and proposal, which was awarded \$100,000 in outside funding to purchase 50 new computer systems. While Budget Advisor, he lobbied for, and received, over \$2 million dollars in funding to implement antiterrorism measures in the wake of September 11th.

Will recently redesigned the Foundation's database and website. The new database streamlines several databases into one that has reduced processing time by 40%. You can see his most recent work on our website. Will has added new features to make things easier for our visitors to navigate the site and communicate with the foundation.

Will received his A.A.S in Criminal Justice from the Community College of the Air Force and is perusing his B.S. in Business Management from the University of Phoenix. He resides in the SF Bay Area and is the father of three children, William (11), Haley (6), and Alannah (3). When Will is not working late at the office, he enjoys golf and spending time with his friends, family and children. •

WHY DOES YOUR BODY ATTACK ITSELF? IT IS DOING WHAT IT THINKS IT IS SUPPOSED TO DO

AUTOIMMUNITY

by Grant Anhalt, M.D.



The function of the immune system was critical to survival of our species. Prior to the 20th century man's greatest killers were, in fact, infectious diseases. It is important to note that not everyone's immune system functions in the same way because genetic diversity determines how one individual will react to a given infection. Diversity in the immune response has protected us from devastating events. For example, not everyone who got the bubonic plague died. Some individuals had a genetically programmed immune response that was more effective than others and they were able to survive. There are many examples of that throughout history of our species.

Because of this the immune system has to be adaptable enough to identify even infectious agents that hadn't existed before. The HIV virus is a good example. To generate such enormous diversity, the controls of the immune system are extraordinarily complex. For these reasons, autoimmunity - which is a malfunctioning of the control of the normal immune system - is also complex and multi-factorial.

A reporter asked me a very important question, "Why should I put an article about pemphigus in my paper since it is such a rare disease and only affects such a few number of people?" Well, the answer is that autoimmune diseases are actually the 3rd most common human ailment behind cardiovascular disease and cancer. The prevalence of autoimmunity has been under-appreciated because many of the diseases are so organ specific that they fractionated to the "turf" of individual specialties. For example, thyroiditis is an endocrine problem. Lupus is a rheumatologic disease. Inflammatory bowel disease is seen by gastroenterologists. Multiple sclerosis is a neurologic disease. However, if you lump all autoimmune diseases together, it is an incredible important problem for our population. Advances in understanding one autoimmune disease can often translate into better understanding of other autoimmune diseases.

What are the key components of the immune

system? There are cells that are called antigen presenting cells. These cells ingest and process foreign organisms such as a virus, a fungus, or bacteria which invade the body. They are then presented to the immune system so that the immune system can respond. There are two different kinds of cells that direct the immune response: T-Cells and B-Cells. These are your soldiers of the immune response. T-Cells are the killer cells and the production of protective antibodies is directed by B-Cells. Some B-Cells mature into plasma cells and they produce a serum protein called an antibody. These antibodies then protect you against foreign organisms. For example, when you get a diphtheria shot as a child, you make antibodies against that diphtheria toxin and those antibodies neutralizes any toxin they encounter. These antibodies keep some diseases away.

In pemphigus, the key players are antibodies because the disease and the damage to the skin is caused by antibodies. Not by the killer cells - T-Cells, but by antibody. Actually antibodies look like a little a "Y". Antibodies directed against the skin attack the skin cells and cause them to fall apart.

The immune system is very specific. Certain cells are programmed to produce certain antibodies. It is kind of a lock and key type recognition system. Antibodies will bind to only those proteins that it is programmed to bind against. In pemphigus, desmogleins (the "glue") in

skin cells are recognized as an invading organism. Antidesmoglein antibodies are then produced. Pemphigus is difficult to treat and there are known reasons for that. Antibodies in the normal state are directed against invading organisms and are protective proteins. These antibodies are protective proteins with long half lives, and cannot be destroyed because they are not recognized as being harmful to the body. The immune system thinks it is doing "the right thing" by producing autoantibodies against pemphigus antigens.

Antibodies last a long time; they have a half life of about 3 weeks. Once programmed to respond they are very durable. So the disease is not going to respond to treatment rapidly. It takes time - time and a lot of intensive therapy over months and years to try to down regu-

"...autoimmune diseases are actually the 3rd most common human ailment behind cardiovascular disease and cancer."

Continued on page 9...

STAND AND BE HEARD! IPF JOINS OTHER ORGANIZATIONS IN ADVOCATING RESEARCH**IPF'S FIRST CAPITOL HILL DAY**

To be a part of the democratic process, we will sponsor our first **Capitol Hill Day on September 23, 2005**, in conjunction with our 8th Annual Patient/Doctor Meeting that will be held in the Washington D.C. area, on September 24, 2005. Because of prices, we are looking at the Hilton hotel in Arlington, VA just across the river from D.C. The D.C. subway system is excellent and there is a station just underneath the hotel that will take us to the Senate and House buildings.

Because pemphigus and pemphigoid are such rare diseases, it is up to all of us to let our Congressional Representatives know who we are and what we need them to do for us. For the last several years, the IPF has been advocating as part of several coalitions on Capitol Hill. We have been asking Congress to not forget how important medical research is and that skin diseases can be very serious – even life-threatening.

Since we were advocating with other organizations, we focused only on the issue of research. But, there are many more health issues which have to be identified and talked about.

If you would like to take part in **Capitol Hill Day – Friday, September 23, 2005**, fill out the form on the next page and let your voice be heard. Give us the name of your Congressional representative and the two Senators from your State. We will work to get you appointments at your House and Senate representative's office. We would like to get appointments made before Congress goes out for summer break. The deadline to return the form is **June 1, 2005**. There will be a charge of \$50.00 per person to cover the cost of breakfast, lunch and transportation to and from the hotel to Washington D.C. and back.

The tentative schedule will be as follows. (*times to be determined*)

- Breakfast and opening remarks at the hotel
- We will depart for Capitol Hill
- Capitol Hill visits (House of Representatives)
- Lunch (Capitol Hill)
- Capitol Hill visits (Senate)
- Return to the Hotel

As we solidify our plans, more information regarding Capitol Hill Day will be on our website. Because the next newsletter will not be out until June 1st, we will be sending out a mailing with information on both Capitol Hill Day and the Annual Meeting sometime in April. If you have any questions, please contact us at **510-527-4970** or by e-mail: **jsegall@pemphigus.org** •



International Pemphigus Foundation 1st Capitol Hill Day

Yes, I would like to be a part of Capitol Hill Day on Friday, September 23, 2005

Name: _____ Date: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Phone: _____ E-mail: _____

My House Representative is: _____

I do not know my House Representative's name. Can you find out their name for me?

The names of my State Senators are:

1. _____

2. _____

These are the issues that affect me: (Please number in order which ones affect you – most to least, 1 to 5)

- Exorbitant prices for our drugs, even with the co-pay.
- No coverage for a middle class working individual who has no insurance and cannot get any with a diagnosis of pemphigus or pemphigoid.
- The trouble that ensues when a patient tries to apply for disability. Not only does a person have to deal with a scary life-threatening disease, but now they have to deal with unfriendly and unsympathetic insurance companies and HMO physicians.
- The undeniable need for more doctors who will treat rare chronic diseases
- Other _____

Please send the completed form to the IPF before **June 1, 2005** to:

International Pemphigus Foundation

Attn: Capitol Hill Day
828 San Pablo Ave., Suite 210
Albany, CA 94706

*Continued from **AUTOIMMUNITY**, page 7...*

late that effect. The other problem is that we don't know how to block the instructions from the immune system that reacts against a single protein, such as to block that one protein against desmoglein.

In PV we know of 2 specific genes that are involved with the disease process. In Jews it is the DR4 gene, and in Northern India, China and Japan it is DQ1. There are also other less frequent genes that can predispose a person to this disease, but these are the key ones.

The basic approaches used to treat pemphigus are: Prednisone, Immunosuppressive drugs, and new therapies like IVIg and Rituximab. However, to date there is nothing that targets the specific protein. The Peptimmune trial drug, if it works, will target the specific protein. •

INTERNATIONAL SCIENTIFIC MEETING SET FOR JUNE 16-17, 2005 IN BETHESDA, MD

PEMPHIGUS 2005: PROGRESS AND FUTURED DIRECTIONS

The International Pemphigus Foundation (IPF) and the American Autoimmune Related Diseases Association (AARDA) are sponsoring an international scientific conference on recent advances in our understanding of the causes and treatments for pemphigus. The conference, funded by a grant from the National Institutes of Health (NIH), will bring together leading experts and other individuals interested in this disease. The latest information available about pemphigus will be disseminated and discussed, with the ultimate goal of improving its treatment. This meeting is not a patient meeting. However, if you are a patient who understands the science of pemphigus, you are welcome to attend.

Dates: June 16-17, 2005

Location: National Institutes of Health, Bethesda MD

Lodging: Rooms have been reserved at the Four Points by Sheraton, Bethesda. Mention the IPF for a reduced rate.

Organized by:

Jean-Claude Bystryn, M.D.

Luis Diaz, M.D.

Sergei Grando, M.D., Ph.D.

John Stanley, M.D.

REGISTRATION INFORMATION

There is a US\$75.00 registration fee for this event. More details on registration and poster submissions can be obtained online at: www.pemphigus.org/2005Meeting.htm. If you would like to receive registration and poster information by e-mail send your request to meeting@pemphigus.org. If you would like to have a packet sent to you by postal mail, call 510-527-4970, or fax your request with your name and address to 510-527-8497. •

**SCHEDULED
ITINERARY**

THURSDAY, June 16

- The Goal of it All: Pemphigus from a Patient's Perspective
 - Mechanics of Keratinocyte Adhesion and Dysadhesion
 - Immune Mechanisms in Pemphigus
- What Causes the Disease: Environment and Genetic Factors
 - Lessons from Other Autoantibody Mediated Diseases

FRIDAY, June 17

- Newer Approaches to the Treatment of Pemphigus
- Open Discussion of Issues Related to Treatment
- The Future—Selective Suppression of Pathogenic Antibodies
 - Workshop

Continued from Q&A page 5

the transplant literature. If you are having trouble with the standard drugs you are taking, Cytoxan is a good drug that would probably treat the disease effectively. Treatment with Cytoxan, however, can cause problems down the line – bladder cancer 7 years down the line or lymphoma leukemia 20 years down the road (although the risk for this is small). Rituximab is a new drug being used on severe PV patients.

Q. How effective is Gold for the treatment of pemphigus?

A. 20 years ago it was used, but many doctors have moved away from using it because there is no evidence that it really works. Reactions to gold can be problematic. Too many serious risks.

Q. What is the definition of long term prednisone use – a year?

Continued on page 11

WHY SUFFER FROM THE PAINFUL, PHYSICAL SIDE EFFECTS OF MEDICATION?

WARM WATER THERAPY POOLS

Using a drug like prednisone, there are all types of side effects that might occur – from loss of muscle strength to aches and pains. One excellent way to help your body recover from these side effects is with aquatic exercise. The benefits of this type of exercise are: general relaxation, reduced joint pain, increased flexibility, improved circulation, improved muscle strength, and increased cardiovascular endurance.

Easter Seals holds aquatic exercise classes in many areas. Recently, we received information about one in Sacramento, CA – 3205 Hurley Way, Sacramento, CA 95864, 916-485-6711, which has a warm water pool therapy program. The water is heated between 92 and 94 degrees at all times.

The pool has a ramp for easy access, handrails along the sides of the pool, a depth range of 3 to 5 feet, shower and locker room facilities and a friendly, supportive atmosphere. To begin the warm water therapy program, you must have a doctor's prescription. When you first start at the warm water therapy pool you will have an orientation with a trained therapist. The therapist will go over with you your particular symptoms, such as muscle problems,

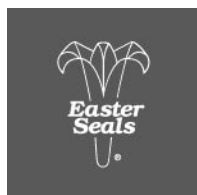
joint pain, or any of the other side effects due to the medications that are taken for pemphigus. The therapist will create a workout program for you to follow to help you regain muscle strength, movement in your joints and reduce pain. You then do these exercises at your own pace

through the Open Exercise Time. While Open Exercise Time continues all day, the pool also offers lap swim time, water walking time, arthritis aerobics, aerobic classes, tai chi and back classes.

They also offer a Pool Pal program, which for a minimal cost, allows you to have a specialist assist

you during your time at the pool. The cost of the pool is \$55 per month and they also have a sliding scale payment program for those with financial difficulties. The pool is open Monday through Friday, 7 am - 7 pm and on Saturdays from 9 am - noon.

Check with your local Easter Seals center to see if there is a therapy pool in your area. •



Continued from Q&A page 10

A. There really isn't any set time as each individual is different in their use. Also, there really are not a lot of choices, so you have to weight the choices of using prednisone, other drugs, or having pemphigus which is a life-threatening disease.

Q. Are the antibodies something you are born with or does it develop over time?

A. Antibodies develop before you get the disease. You are not born with it. There is, however, a genetic predisposition to the disease. With the genetics, we

know some of the genes that are active, but we don't know all the genes.

Q. How would you counsel a woman who has pemphigus on Imuran and prednisone on what to do in case they want to get pregnant?

A. We do not know what happens with the disease when a patient gets pregnant. There isn't a proven effect of neither suppressing or causing a flare of the disease. A woman who of child-bearing potential should not be on Fosamax or Atenol because it takes very long for

those to clear. They need to be off of Fosamax for at least 500 days, less for Atenol. If a woman does become pregnant and the disease flares, the only drug you can use safely is prednisone which does not cross the placenta. Effects to the fetus are indirect. As long as the mother is healthy and doesn't need excessive doses of steroids, the baby will be healthy. The stress of pregnancy and steroids on the mother can pre-dispose her to hypertension, diabetes, and other complications. •

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WHAT DO A DOCTOR AND A PATIENT HAVE IN COMMON REGARDING RITUXAN? THEY TELL YOU...

WHAT YOU NEED TO KNOW ABOUT RITUXIMAB

By Dr. Grant Anhalt

Johns Hopkins Medical Center
Baltimore, MD

Rituximab is a monoclonal antibody that targets CD20+ B-cells. Rituximab is a laboratory manufactured antibody that targets the cells in our bodies that produce antibodies. This was genetically engineered and is the first monoclonal antibody to be approved by the FDA for the treatment of cancer. The current indication for its use is in the treatment of non-Hodgkin's lymphoma. It has become an important tool for patients with that disease.



What does it do?

The CD-20 molecule is present on B-cells as they mature. However, since they are not present on stem cells, stem cells are not affected. So, what the drug does in autoimmunity is interrupt the chain of command between the T-cells, B-cells, and plasma cells (a mature B-cells) which are not affected by the drug. It binds to the CD-20 molecule on the cell surface of the intermediate B-cells and kills them.

Are other cells killed too?

Although it kills off this population of B-cells, it turns out to be safe because it is not profoundly immunosuppressive. Plasma cells are not killed and it doesn't seem to interfere with normal protective antibody coverage.

How do I take Rituximab?

Rituximab is given by IV infusion – once a week for 4 weeks taking about 3 to 4 hours. If there are initial problems, the infusion can last much longer. The dose is usually about 500-700 mg. The removal from the blood can be followed by using an instrument called a flow cytometry. Please note, the time of infusion can be as long as 6 to 8 hours.

How often do I have to take Rituximab?

As stem cells are not killed, the CD20 positive B-cells begin to repopulate within about 6 to 12 months. Rituximab is expensive, but less expensive than IVIg. Total drug cost is about \$10,000 for one 4 week treatment.

PV is not the only autoimmune disease for which this drug is being explored. There is evidence it is helpful in other autoimmune diseases, such as ITP (idiopathic thrombocytopenic purpura) and other diseases including Rheumatoid arthritis. The drug is often used in combina-

tion with other standard immunosuppressive drugs.

Experience in PV is limited. To date, there are no formal trials going on at present for Rituximab. However, there are some impressive case reports. At present it is used more frequently in patients with paraneoplastic pemphigus than in pemphigus vulgaris or foliaceus. Some problems with infection after treatment with Rituxan have been reported. Rituximab eventually could become a good tool for treatment of PV. Our biggest problem with this class of drugs is to know how to most effectively use these expensive drugs, define which patients will benefit the most, and who will respond the best.

Milo Careaga is a PV patient using Rituximab. He has added this information from his own research and experience.

What are the side effects?

Most of the problematic side effects occur while treatment is given. These include reactions similar to allergic reactions, and can be very serious or even lethal (just as a bee sting can be for some people). However, to reduce the risk of side effects during administration of Rituxan patients are given Benadril and Tylenol, and in some cases cortisone. In addition, the rate of infusion seems to be related directly to problems, so slowing the infusion rate typically alleviates any problems.

The biggest problem is one seen by all immunosuppressive drugs – **immune suppression**. Since the many of the body's B-cells are destroyed, after a few months your supply of antibodies will "dry up" and you will be more vulnerable to infection. Unlike typical chem. meds, Rituxan leaves your T-cells and the rest of your immune system intact, so you are still fairly protected. The problem is that if you become infected with something more severe, like the flu, your body will have a very difficult time mounting a defense against it.

Will I lose my hair and be nauseated like Cytoxan?

Cytoxan, and many of the cytotoxic chemotherapy medications work by killing rapidly reproducing cells. This affects the cells of the gut and hair follicles which rapidly reproduce and can cause hair loss and nausea in some people. Rituximab does not work in this way, and therefore should not cause hair loss or nausea. Nausea might appear as a result after infusions or during, but should pass and should not be persistent. •

BY GIVING A LITTLE YOU HAVE HELPED A LOT...THANK YOU EVERYONE!

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The International Pemphigus Foundation is deeply indebted to all those who contributed to our cause; the fight against pemphigus and pemphigoid. Because of your generosity, our fight will continue well into the future. Thank you very much. Show are donors who contributed \$50 or more. Although space does not permit publishing the names of all those who made contributions under that amount, we extend heartfelt thanks to them as well.

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