



Handling Steroid Sparers

What vitamins can help you handle the other drugs you take?

See page 6

Lost Ground at Work?

Rosalind Joffe outlines 7 ways to get back on track in the workplace.

See page 8

Multiple Causes Named

Dr. Sarah Brenner spells out an acronym for the disease with many possible causes.

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IPF Awards \$10,000 Grant to the Mayo Clinic

The IPF has awarded a grant of \$10,000 to Dr. Mark Pittelkow, Mayo Clinic in Rochester, MN. Dr. Pittelkow will lead a research team focusing on "Epidemiology of Pemphigus in Olsted County, Minnesota Between 1950 and 2000."

As research on pemphigus has been hampered by the lack of defined populations, Dr. Pittelkow's group objective is to identify factors or risks that correlate with the development of pemphigus. Environmental factors are involved in the disease process and course of pemphigus. However, no data on a defined North American population has been published to date. The long-range goal is to develop new therapeutic strategies for pemphigus.

There is a long-standing tradition of performing extensive epidemiologic studies in Olmsted County,

MN. Olmsted County lies 90 miles southeast of Minneapolis-St. Paul. Olmsted County, MN has been served by a largely unified medical care system that has accumulated comprehensive clinical records since early 1900's.

The group will identify all patients who were residents of Olmsted County and received a diagnosis of



Dr. Mark Pittelkow
Professor,
Dept. of Dermatology

Dr. Mustafa Al Hashimi
Associate Professor
Dept. of Dermatology

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Peptimmune Receives FDA Clearance for Phase I Clinical Trial

Peptimmune has received clearance from the FDA to conduct a Phase I clinical trial to assess the safety of their drug PI-0824 in patients with pemphigus vulgaris requiring daily corticosteroid therapy. They have also received IRB approval from NYU, one of the clinical sites, to begin enrolling patients there now. Other sites will hopefully follow over the next couple of months. The Foundation is very pleased with Peptimmune's efforts to help patients with PV and hope that the trial will proceed smoothly.

Pemphigus vulgaris (PV) is an autoimmune disease affecting approximately 40,000 people worldwide. People with PV produce antibodies that attack the cells of the skin, resulting in blisters which, if left untreated, can lead to devastating infections and discomfort. Currently, most doctors who treat patients with PV will prescribe high-dose steroids and drugs that suppress the immune system in an effort to decrease the production of these antibodies. Unfortunately these medications are associated with serious and difficult side effects that often result in the discontinuation of their use.

Peptimmune, Inc. is developing a new therapy for the treatment of PV, PI-0824. The goal of this therapy is to reduce the production of antibodies that cause PV blisters by acting only on the disease causing components of the immune system. It is hoped that use of PI-0824 will reduce or potentially eliminate the need for high dose steroids and drugs that suppress the immune system.

To be eligible for this study patients must have PV only, and be 18 years or older. Both males and females are eligible. Patients should currently be experiencing stable disease with a stable medication regimen that includes daily corticosteroid therapy for their PV.

The total number of patients for this phase of the study is expected to be 15.

At present, the only location ready to accept patients: New York: NYU School of Medicine, New York, New York, 10016, United States; Recruiting: Bruce Strober, MD 212-263-5244; Lorrie Jondreau, RN 212-263-5244; Bruce Strober, MD, PhD, Principal Investigator. ☒

Register for the Annual Doctor/Patient Meeting today!
See page 5 for details and a registration form. Deadline for registration is October 1.

THE VIEW FROM HERE

Approaching the 10 Year Mark



Janet Segall,
Executive Director, NPF

Next year, the IPF will be celebrating its 10th anniversary. We have accomplished so much. All of these accomplishments are due to the help and assistance of many volunteers over years of hard work – the Board of Directors, staff, the Medical Advisory Board members, other physicians on our referral list who have supported our organization, support group leaders, Heart to Heart volunteers, and so many others who have contributed time and effort to help us. I would also like to thank all of our generous donors, with a special thanks to all who donated to this year's Summer Fundraiser.

Along with our volunteers, we have received mentoring from many leading CEO's in the voluntary healthcare community and officials at the National Institutes of Arthritis Musculoskeletal and Skin Diseases (NIAMS), an Institute at the National Institutes of Health (NIH). We have met doctors from all over the world who are working with us to bring better information and care to their patients - in the Philippines, England, Germany, Italy, the Middle East, and as far away as Croatia, Turkey, Australia and Brazil.

The contacts we have made in the medical community have allowed us to provide what I believe to be one of the most important elements of our mission - uniting patients, especially in times of extreme difficulty, with the right doctor. In these last few weeks I have been talking with several families who were having trouble getting the right medical help. That often means not being able to get past the scheduling staff and often waiting weeks or months before getting an appointment.

Because of the IPF's relationship with so many of the leading doctors in the field of treating pemphigus and pemphigoid, we have been successful in helping people get the assistance they need in a timely manner. An older gentleman was having trouble with his CP. Unfortunately, he was also having trouble finding a doctor who knew about the disease. We were able to connect him with the appropriate physician who took him in immediately. Some time ago, we received a frantic call from the husband of a woman who was in the hospital and, in his words, "Help us, please, the hospital is killing her. They don't seem to know what to do." We put him in contact with Dr. Anhalt and the woman's life was saved.

Helping patients get the right information, find the right doctors, and get the emotional support they need are among the main goals of this Foundation, but behind the scenes, the IPF is also involved with several important organizations that do important work as patient advocates. We are members of the National Health Council (NHC). The NHC is comprised of 115 organizations and companies dedicated to patient advocacy. As mentioned in this newsletter, they are launching their new initiative Putting Patients First®, and we are privileged to lend our support. We belong to the Coalition of Skin Diseases (CSD). The Coalition's main focus is to help convince Congress to give more money to the NIH for research. We spend one day visiting many different Representatives and Senators educating them on how imperative it is that the NIH get the financial support they need. Even if the money allocated for researching pemphigus and pemphigoid directly is small, there are research projects that they are funding on autoimmunity that could ultimately help all of us. Our association with the American Academy of Dermatology (AAD) through their physician membership, and the Coalition of Skin Diseases has provided us with a lot of information and assistance, and we have supported the American Autoimmune Related Diseases Association (AARDA)'s Coalition, which has convinced Congress to enact legislation to establish a Committee of Autoimmunity at the NIH. This important step could ultimately bring more research money for pemphigus and/or pemphigoid research. With the help of AARDA, the NIH, and several pharmaceutical companies, we were able to host our first international meeting on pemphigus in 2001, with a follow-up planned for 2005. We have also been working with Congress to increase federal support for pemphigus and pemphigoid research. We are members of the California Association of Non-profits (CNP), which provides us with the most up-to-date and professional

International Pemphigus Foundation

"A common hope, an uncommon bond"

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.

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Philadelphia, Pennsylvania

HEADQUARTERS:

Atrium Plaza, Suite 210, 828 San Pablo Avenue, Albany CA 94706
Phone: 510-527-4970 Fax: 510-527-8497
pemphigus@pemphigus.org Website: <http://www.pemphigus.org>

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THE VIEW FROM HERE, *continued*

information on running a successful organization. We are making great strides.

This year, as mentioned in this newsletter, are the details of the first \$10,000 grant the IPF has just awarded to a research project at the Mayo Clinic in Rochester, Minnesota. We are very excited about awarding this grant. There are very few epidemiology studies in the world on pemphigus. This study could lead to some very interesting results. They are considering a project regarding pemphigoid.

As we celebrate our 10th anniversary in 2004, we begin a new era for the Foundation. We have developed several new programs and have expanded the ones we have. As part of our Information Research Center which includes our website and our newsletter, our booklet "Pemphigus - An Introduction" is now available on our website. The Pemphigoid booklet is almost complete. We are also working on several pamphlets on subjects such as caregiving and nutrition.

We have begun our Doctor Education Program that enables doctors to talk about

the rewards of treating pemphigus and pemphigoid patients to new physicians. We have received very positive support from our Medical Advisory Board regarding their participation in this program. Very soon, we will be announcing a new PR campaign that will bring more attention to our diseases.

I am very excited about the future. With the help of patient volunteers, Peptimmune has begun its Phase I Clinical Trials on a new drug that could revolutionize treatment not just for PV, but for all types of pemphigus, pemphigoid and autoimmune diseases in general.

Volunteering

We have been able to accomplish all these goals because of you. Volunteers are an important part of making the IPF the best organization supporting patients with pemphigus and pemphigoid. They are the backbone of this organization. And we need more help. We need someone to help us write grants. We want to give a research grant every year. We want to provide a special training

retreat for our support group leaders and people wanting to start a group. We need more volunteers who live in or near Washington D.C. to represent us at several NHC and AARDA committee meetings in the area which the staff cannot attend. We need people willing to write articles for our newsletter - articles on different aspects of the disease such as nutrition, living with chronic illness, caregiving, alternative medicine that might help with drug side effects, or just an uplifting personal story that will help many understand that there is living with their disease.

These are just some of the things we could use more help with. If you have expertise that you think would help make the IPF more effective, please contact the office. There is nothing - nothing more exciting than knowing that something you've done has made a difference in someone's life. I believe that it is so important for a community as small as ours work as one. We need to support each other, and work together to defeat these diseases. ☞

MEDICAL NEWS

The National Health Council – A National Initiative: *Putting Patients First*[®]

The National Health Council (NHC) is a membership organization comprised of over 100 national voluntary health agencies, professional associations, businesses and other organizations with a strong interest in health. *The Council is creating a national public education initiative, "Putting Patients First[®]" to empower, engage and activate consumers of health care in the debate on health system design and health policies.* The International Pemphigus Foundation is a member of the NHC. As patient care is our primary goal, we are very pleased to be involved with the NHC's initiative.

There is no mechanism that brings the debate on health care issues to what is best for the patient and what allows the patient to control his/her own health care delivery. The patients' voice is missing. Health care should be centered around patients; not the doctors, or the hospitals, health plans or insurers. Revolutionary changes in thinking must occur in order for patients to become the center of health care.

For this to happen, a national public edu-

cation effort is needed that would connect issues and organizations. Some of these issues would include health literacy, health education, portable medical records, clinical trials, family care giving and end-of-life care.

Current policy discussions on health care are not patient-centered. Most of the dialog on health care is "upside down." In highly technical debates on financing, structure, medical practice, insurance etc., the public is often left out or marginalized. The public conversation is often a debate about Medicare, Medicaid, medical malpractice, etc. All of which are important issues, but none of which include patients as partners in the development of systems and policies.

This important initiative will enable voluntary health and consumer organizations to advocate as a united voice for patient-centered care. An umbrella public education initiative that includes web-based "virtual" elements will create a way for the voices of patients and their families to be organized and speak out on wider issues of health care.

The *Putting Patients First*[®] initiative will

be implemented in stages. The first stage will include a review of current and past polling. In addition, in order to understand what patients want from the health system, the initiative will include conducting a series of focus groups with patients and their families to develop language that will be used to address these issues. A National Advisory Commission will be established to link experts in the field and champions of patient-centered care with membership organizations that have the commitment to carry this concept forward.

The next stage of the initiative will include documenting best practices in patient-centered care and implementing the web-based "virtual" elements of the initiative to engage the public in advocating for patient-centered care.

Through this initiative and its many elements and activities, the Council and its member organizations will unite to enable consumers to inform health care policy decisions and ensure a patient-centered health care system in the 21st century. ☞

FROM OUR READERS

A Pemphigus Story from Down Under

by *Therese Kay, Australia*

Dear Fellow Patients!

My pemphigus vulgaris started some 5 years ago. My doctor sent me to the dentist, who sent me to a physician, then to an oral specialist who had one look, took a biopsy and bingo, pemphigus. High dose of cortisone, which soon became a sickness of its own, my skin is like tissue paper, bone loss, my teeth had nothing to hold their roots so they broke off, eating became difficult. Where most pemphigus patients put on weight from prednisolone, I lost weight and am now 47 kg. I became weaker and weaker. To convince my family what I went through was not easy, but they all stood by me and helped out.

Meantime, to top things up, my thirteen-year-old artificial aortic valve needed replacing. I remember having an appointment with the heart specialist. I took a taxi there and the driver dropped me off at the wrong hospital in pouring rain. I tried to hail another taxi, but none stopped. I dragged myself along. All I wanted was to sit down on the pavement and die. When I reached the hospital they had one

look at me and brought a wheelchair. The heart specialist studied everything and advised against another operation, go home, enjoy your seven grandchildren till the end. I asked, "What are my chances?" "25% you'd die on the table!" I opted for the 75% left. I remember like today the morning of the operation I was wheeled to the operation theatre when a young doctor came running up and put a mobile to my ear, and there was Yoni, my grandson, telling me that all my grandchildren were praying for my recovery. I got over the operation, but my pemphigus got worse, some days I could hardly speak. I cried most nights from pain and despair. Distractions helped temporarily, arguments caused a flare up. A sense of humor does wonders. My loved poetess, Ella Wilcox, wrote there is room in the halls of pleasure, for a large and lordly train, but one by one we must all ride on, through the narrow isles of pain.

I have good news. By coincidence, I came across a liquid called "Swedish Bitters." It is sold at health food shops, made by a lady Hilde Hemmes from Austria, who used the roots of eighteen herbs to concoct this liquid. She is well recognized by the Australian

School of Herbal Medicine. I was to take two teaspoons in a half glass of water, take a mouthful and hold in your mouth for 3-5 minutes, spit out, repeat three more times. After one week, all the pain in my mouth went away. I can sleep, eat and speak without pain. I still get the blisters and lesions, but not as bad.

Wishing you all well. Thanks to Janet Segall and her help and advice. ☺



IPF AWARDS \$10,000 GRANT TO THE MAYO CLINIC, *continued from page 1*

pemphigus from January 1, 1950 to December 31, 2000. In addition, they will identify and review all patients who received a diagnosis of pemphigoid particularly during 1950-1965 to ensure that patients with pemphigus were not classified as having pemphigoid during those early years when distinct autoimmune diseases were initially being better characterized and separated by tissue immunofluorescence and serologic analysis. Once potential cases are identified, complete inpatient and outpatient medical records of each subject will be reviewed. Also family and personal medical history including oral contraceptives, pregnancies, abortions, smoking habits, and exposure to gardening, farming, photographic developing or other occupational or vocational chemical exposures such as pesticides, tar or industrial solvents, and emotional stress will be evaluated.

This study has several limitations. Because Olmsted County is predominantly white and middle class, the research findings may not be directly applicable to other populations. However, the characteristics of the Olmsted

County population are similar to those of the U.S. white population.

To accomplish these objectives, the group will pursue four specific aims:

1. **Determine the age, gender, and ethnic-specific incidence and prevalence of pemphigus**, and identify pemphigus subtypes, including paraneoplastic pemphigus in Olmsted County residents between 1950-2000.
2. **Evaluate all available demographic and clinical characteristics** of Olmsted County individuals with pemphigus.
3. **Determine the overall treatment response for oral corticosteroids** as well as steroid-sparing effects of alternate systemic and local medications by evaluating types and effectiveness of pemphigus therapy among Olmsted County residents.
4. **Identify risk factors for development, severity, relapses and death due to pemphigus**. Specifically, it will be determined whether demographic characteristics, severity of initial clinical presentation, average initial autoantibody titer, treat-

ment type and duration, other medical conditions/co-morbidities and environmental factors, including recreational and occupational exposures, drugs, and smoking are associated with the onset, severity, initial therapeutic response, risk of relapse and/or death due to pemphigus.

The proposed project has several appealing features. The expected data are likely to allow us to better understand some aspects of pemphigus and its treatment. Therefore, the results of this proposal might form the basis for new research directions potentially allowing the development of novel pharmacologic targets or immunotherapy to eliminate or modulate disease-causing immune factors. In addition, this study can be extended to prospective analysis of risk factors and also to correlate with newer immunogenetic and molecular findings on pemphigus.

This study attempts to identify new correlations for onset and severity of disease as well as, eventually, more effective therapies and prophylaxis for pemphigus based on exhaustive epidemiologic analysis of the unique data. ☺

2003 PATIENT/DOCTOR MEETING

Reserve your Spot at the Meeting by October 1st

Registration for our 6th Annual Patient/ Doctor Meeting has begun. This year the meeting will be held on November 8, 2003, hosted by the Cleveland Clinic in Weston, Florida just outside of Ft. Lauderdale.

We are looking to have another terrific meeting (and maybe play a little golf as well). Since there are many pemphigus and pemphigoid patients in and around the Ft. Lauderdale area, we looking forward to this meeting.

The speakers will include Drs. Nousari, Anhalt, Cohen, Elgart and Sciubba. **Dr. Carlos Nousari**, as of September 1st, will be taking over as Chairman of the Dermatology Department at the Clinic, and is responsible for the meeting taking place at the Clinic. **Dr. Carlos Cohen** is a member of the physician staff at the Clinic and deserve a thank you for helping us set this meeting up. He has also helped provide us with additional speakers.

Dr. Grant Anhalt is the Head of the Dermatoimmunology Department at Johns Hopkins University School of Medicine in Baltimore, as well as a Board member and Head of our Medical Advisory Board.

Dr. George Elgart is Associate Professor of Dermatology at University of Miami.

Dr. James Sciubba is the Director of Dental



and Oral Medicine at Johns Hopkins University School of Medicine and will be discussing the problems and solutions of oral disease.

Also speaking will be **Dr. Andrew Ukleja**, a gastroenterologist at the Cleveland Clinic with expertise in nutrition.

Our morning activities will include talks from the doctors on the disease. In the afternoon we will have Dr. Ukleja speak, our physicians panel, and psychologist, Dr. Karen Mallin. Janet Segall, Executive Director, and Jean Barish, Board President will also speak.

In the evening, we will hold our annual dinner at the Wyndham Hotel in Ft. Lauderdale. We have blocked 25 rooms for those people who will be coming from out of town at the Wyndham Hotel, 250 Racquet Club Rd., Ft.

Lauderdale, 954-389-3300. Rooms will be \$89.00 per night + 11% sales tax. Rooms will be held until by October 7 at the lower rate.

On Sunday morning, we will launch a support group for Fort Lauderdale and the surrounding area. If you are interested in participating, please check the appropriate box on the registration form below.

The cost of the meeting, which will include 3 meals, will be \$125 per person. If the cost is a financial hardship for you, please contact the IPF office.

If anyone wants to play golf, we will be signing people up for a Sunday afternoon round of golf at the Bonaventure Country Club just across from the Wyndham Hotel. The cost for golf will be \$44 per person. We will not be collecting money for golf now, but when we have more details on it, we will contact all of you who have shown interest.

If you would like to attend this year's meeting, please fill out the form and send it back to the International Pemphigus Foundation, 828 San Pablo Ave., Suite 210, Albany, CA 94706 with your payment. If you have any questions, please call us at: 510-527-4970. MasterCard or VISA only will be accepted. ☑

2003 Patient Doctor Meeting Registration Form (Registration Deadline: October 1)

Name _____

Address _____

City _____ State _____ Zip Code _____

Phone # _____

E-mail _____

Number of people attending _____

If more than just yourself, please provide the names of additional attendees:

_____ person(s) @ \$125.00 Total _____

_____ Credit Card Number (VISA or Mastercard only) Exp. Date _____

Billing Address for Credit Card if different from address at left:

Address _____

City _____ State _____ Zip Code _____

Please check here if you would like vegetarian meals.

Please check here if you would like to participate in the Fort Lauderdale support group.

Please check here if you would like to play golf on Sunday.

_____ Number of people who will be joining you for golf.

Coping with Adjunctive Medications

by Jennifer Williams

As all pemphigus and pemphigoid sufferers are quite aware, high doses of steroids are generally used in the first phase of treatment to control the blistering. Often to relieve the unpleasant side effects of such great doses, an immunosuppressive drug (used to prevent production of antibodies) is added into the mix to lessen the steroid dosage. As the side effects of steroids subside, patients are faced with a new challenge: coping with side effects of the immunosuppressive drugs.

It is important to remember that most people tolerate these drugs well, and that all the possible side effects do not happen in every person.

The most commonly prescribed drugs for pemphigus or pemphigoid patients are:

CellCept is a powerful immunosuppressant used as therapy to prevent organ rejection. The most common side effects associated with CellCept include diarrhea, leukopenia (reduction of white blood cells), sepsis (illness caused by infection of the bloodstream) and vomiting.

Azathioprine (Imuran) is an immunosuppressive antimetabolite. Antimetabolite means that it blocks the normal division (mitosis) and functions of cells. It is another anti-rejection drug taken by transplant patients. Side effects include nausea, vomiting, fever, chills, loss of appetite, diarrhea, shortness of breath, blood in the urine or stool, unusual bruising, fatigue, missed menstrual period, yellowing of the eyes and skin, hair loss, muscle or joint pain, and darkening of the skin and fingernails.

Cyclophosphamide (Cytoxan) is an immunosuppressive often used in the treatment of cancer. It interferes with the multiplication of specific cells and slows or stops their growth and spread in the body. Side effects can include nausea, vomiting, decreased blood counts (bone marrow depression), hair loss (Alopecia) and irritation of the bladder.

Cyclosporine, is an immunosuppressive used to prevent rejection of kidney, liver, and heart transplants. Common side effects are upset stomach, vomiting, diarrhea, loss of appetite, increased hair growth and sinusitis.

Methotrexate, an antimetabolite, is generally used as a treatment for many types of cancer. It can cause temporary reduction in the

production of blood cells by the bone marrow, sore mouth and taste change, diarrhea, fatigue and a general feeling of weakness.

Dapsone (DDS) is an antibiotic used to treat leprosy, skin infections and pneumonia. Side effects consist of upset stomach, vomiting, sore throat, fever, rash, yellowing of the skin or eyes and unusual bruising.

Tetracycline and Minocycline are antibiotics often used to treat skin diseases. Increased sensitivity of skin to sunlight (rare with minocycline) is a common side effect. Less common reactions include abdominal pain, headache, loss of appetite, nausea and vomiting, visual changes and yellowing skin.

Hydroxychloroquine (Plaquenil) is an antimalarial used most often to prevent and treat acute attacks of malaria. The side effects vary widely with each individual, but can include difficulty breathing, dizziness, loss of appetite, constipation, diarrhea, vomiting, insomnia, anemia, hair loss, blood, kidney, stomach and liver problems and gastro-intestinal problems.

On the facing page is a list of foods that can combat some of these side effects. Foods are generally the best way for your body to absorb the vitamins and minerals it lacks. If you have trouble with any of these foods, you may want to consider a supplement. An important note to consider is that too much Vitamin B-complex or Vitamin C can boost your immunity, therefore reducing the effectiveness of the immunosuppressive and steroid treatment.

Liver problems can also occur with immunosuppressives and some of the other drugs. Milk thistle may be very effective in helping to bring the liver functions back to normal. Evidence exists that milk thistle may protect the liver through a number of mechanisms: antioxidant activity, toxin blockade at the membrane level, enhancement of protein synthesis, antifibrotic activity, and possible anti-inflammatory or immunomodulating effects. A with any supplement they may be some side effects, but the reports on side effects have been minimal.

Remember, do not take anything without the permission of your doctor, and check with your doctor or your pharmacist for any interaction between any drugs

you are taking and any over-the-counter drugs you might be taking.

Additionally, sipping various herbal teas such as fennel, ginger, chamomile, fenugreek, lemon balm and peppermint throughout the day, should promote calmness and general well being.

The most important idea to grasp from this article is that eating whole foods and avoiding processed foods as much as possible will contribute greatly to your health and to lessening the magnitude of the side effects. For instance, choose whole wheat pastas and breads, brown rice, high-fiber cereals, fruits and vegetables. It is also important to get as many omega-3 essential fatty acids or polyunsaturated fatty acids as possible. They are found most abundantly in flaxseed (linseed) oil, rapeseed (canola) oil, chia seeds, walnuts and walnut oil, the Mediterranean plant, purslane, grass-reared meat, and dark green leafy vegetables. Oily fish are another rich source; herring, mackerel, sardines, pilchards, salmon, and trout. Fresh tuna is a good source, although canned tuna is not as the oil is lost in processing and replaced by another, eg sunflower or soya oil. Vegetarian omega-3 ALA supplements are available, usually as flaxseed (linseed) oil.

Finding the right combination of foods and vitamins to reduce the effects of drugs can be tricky and time consuming. Sometimes, taking something for the side effects of immunosuppressives could enhance the side effects of steroids. *It is extremely important you keep in mind that overdoing anything is probably not good for your system.* For example, doctors tell you to eat a lot of fish for Omega-3 fatty acids. However, some fish are high in mercury and other chemicals so eating too much fish could be detrimental.



NUTRITION NEWS

To get enough Omega-3s there are other foods you can add in such as walnuts and soy-bean products. There can also buy Omega-3s at your local health food store.

As always, we tell people who are sensitive to some foods such as garlic or onions that

might complicate PV, to watch the amounts of those foods. At this stage, the science of food and pemphigus is theoretical. However, there are many patients who have had problems with many of the foods considered triggers for PV.

You can find this information at the following internet websites. ☞

<http://www.naturalhealthcaretoday.com/~aretee/atomworld/vitamins.html>

<http://www.trimurtisolutions.com/rasoi/vitamins.html>

| Symptoms | Helpful Vitamin | Food Source |
|---|---|---|
| Fatigue, insomnia | Vitamin B (Complex) | whole grains, liver and brewer's yeast |
| Depression, constipation, shortness of breath, weakness, fatigue, loss of appetite | Vitamin B-1 (thiamine) | Pork, nuts, wheat germ, poultry, fish brown rice, egg yolks, legumes, whole grains, blackstrap molasses, brewer's yeast, whole wheat, seafood, potatoes |
| Inflammation of the mouth, eye problems, dizziness, poor digestion, sore tongue | VITAMIN B-2 (riboflavin) | cheese, milk, egg yolks, brewer's yeast, nuts whole grains, blackstrap molasses, yogurt, poultry, green vegetables |
| Possible loss of muscle control, nervousness, mouth disorders, irritability, muscular weakness, anemia, arthritis, hair loss | VITAMIN B-6 (pyridoxine) | Milk, cabbage, cantaloupe, legumes, blackstrap molasses, meat, peas, wheat germ, whole grains, brown rice, prunes, fish, leafy green, vegetables, brewer's yeast, prunes, soya beans. |
| General weakness, poor appetite, anemia, nervousness | VITAMIN B-12 (cobalamin) | Pork, beef, cheese, milk/milk products, eggs, fish, kidney, cereals, yeast extracts. |
| Exhaustion, loss of appetite, impairment of fat metabolism, muscle pain, depression | BIOTIN (vitamin H) | Sardines, liver, legumes, egg yolks, unpolished rice, lentils, mung bean sprouts, whole grains, brewer's yeast, oats, nuts, wheat germ. |
| Liver, kidney and stomach problems, intolerance to fats | CHOLINE | Leafy green vegetables, heart, lecithin, egg yolks, brewer's yeast, fish, legumes, soybeans, wheat germ. |
| Gastro-intestinal disorders, B-12 deficiency, anemia | FOLIC ACID B-9 (folate) | Root vegetables, tuna, milk/milk products, kidney, liver, oysters, salmon, leafy green vegetables, brewer's yeast, whole grains, wheat germ. |
| Eye problems, high cholesterol, skin problems, constipation | INOSITOL | Citrus fruits, nut, milk, meat brewer's yeast, blackstrap molasses, whole grains, vegetables. |
| Gastro-intestinal disturbances, nervous disorders, muscular aches, loss of appetite, insomnia, tiredness, halitosis | NIACIN B-3 (nicotinic acid) | Beans, green vegetables, rice, bran, whole wheat, nuts, brewer's yeast, fish, dairy products, poultry, lean meats, milk, eggs, cheese, peas. |
| Stomach stress, vomiting, diarrhea, kidney trouble | PANTOTHENIC ACID B-5 | Egg yolks, orange juice, brewer's yeast, legumes, liver, whole grains, mushrooms, salmon, wheat germ, beans |
| Anemia, constipation, tiredness, headaches, digestion problems | PABA (para-aminobenzoic acid) | Leafy green vegetables, yogurt, wheat germ, blackstrap molasses, brewer's yeast |
| Muscular weaknesses, anemia, appetite loss, swollen joints, slow healing wounds & fractures, bleeding gums, easy bruising, low resistance to infections | VITAMIN C (ascorbic acid) | Tomatoes, acerola cherries, sprouted alfalfa seeds, peppers, citrus fruits, papaya, potatoes, cantaloupe, broccoli, strawberries, chillies |
| Muscle weakness, diarrhea, insomnia, nervousness, soft bones and teeth, myopia | VITAMIN D (calciferol) | Fat, butter, fish liver oil, herring, sardines, egg yolks, salmon, tuna, margarine. Also, sunlight on human skin is beneficial |
| Fragility of red blood cells, dry dull hair, sterility, impotency, gastro-intestinal problems, heart disease, enlarged prostate. | VITAMIN E (tocopherol/ tocopheryl) | Margarine, cold pressed oils, whole wheat, sweet potatoes, molasses, nuts, dark green vegetables, eggs, oatmeal, wheat germ |
| Diarrhea, underweight, gallstones | VITAMIN F (unsaturated fatty acids) (linoleic acid) | Butter, wheat germ, vegetables, oils, sunflower seeds |
| Intestinal malabsorption, nose bleeding, diarrhea, cellular disease | VITAMIN K (phylloquinone) | Cauliflower, soybeans, polyunsaturated oils, fish liver oils, egg yolks, yogurt, kelp, cow's milk, alfalfa, leafy green vegetables, blackstrap molasses |
| Tendency to bruise and bleed easily (same as symptoms caused by deficiency of vitamin C) | VITAMIN P (bioflavonoids, rutin, hesperidin) | Buckwheat, black currants, cherries, grapes, fruits |

FEATURE ARTICLE

7 HABITS

for Regaining Power in the Workplace with Chronic Illness



by Rosalind Joffe

Rosalind Joffe coaches individuals to thrive in the workplace. Drawing on 25 years of work experience, living with chronic illness, she helps others to prosper in their work. Rosalind holds a B.S. in Communications and an M.Ed. from Boston University, Executive Coaching Certification from the Corporate Coach Institute, and Family Mediation Certification from Academy of Family Mediators.

COMMON Goals

rosalind@common-goals.com
www.Common-Goals.com

1 Focus On What You Can Control. You may not be able to control the course of your illness. You can control the direction you take and the choices you make regarding that illness in the workplace. View your chronic illness as a challenge to meet, not an obstacle in the way.

2 Ignore The Nay Sayers. Many people will tell you that work is stressful and that rest is best for people with chronic illness. Ignore them. Unpleasant work or too much work is negative stress and it can be bad for anyone's health. Yes, you have more challenges now than you did before, but throwing in the towel is not the only option. Shape your work environment to meet your needs and you'll help yourself.

3 Come Out Of The Closet. Chronic illness is nothing to be ashamed of. If your illness impacts your work, keeping it a secret depletes your precious energy and gets in your way. Maintain your right to privacy and be judicious with your information, but don't take on the burden of pretending that you don't have a chronic illness. Be as public as you need to be and as private as you want to be.

4 Don't Just Survive - Thrive. It's easy to feel that survival is enough. And most people who love you won't expect more from you than that. But chronic illness or not, you weren't born for mediocrity. Raising the bar doesn't mean doing more than you can; it means aim high and seek what you need to thrive. Reach beyond relief; go for the satisfaction.

5 Control The Message. Other people on the job will be looking to you to set the tone, and you can influence the way they respond to your illness. Design and control your message: What and how much do you want to say? Who do you want or need to say it to? When and where do you want to talk? Get out in front of the conversation.

6 Don't Let Your Illness Define Who You Are. Some people might try to paint you as a martyr; others may consider you less worthy of recognition or promotion. Neither extreme works to your advantage; each gets in your way. The message you want to convey is that your chronic illness is simply one of several cards in your deck; just like everybody else. Having a chronic illness is neither a source of shame nor a source of pride.

7 Look for the Silver Lining. Although you may not believe it now, workplace success in the face of illness is transforming. Many of us have found new strength and confidence – qualities we never knew we had – as a result of our illnesses. We have used this new found power to face other life challenges. It need not all be about the bad news.

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410-750-1618, Email: byrnete@comcast.net

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Angela Vickers
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Richard M. Schwartz
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Barbara Roller
818-991-6569, Email: barby43@aol.com

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Mike Main
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Email: mmain@chapterhouse.com

New York

Matt Koenig
516-825-4594, Email: mattkoe@aol.com

Philadelphia

Barbara Sipe
215-662-6446

San Francisco Bay Area

Janet Segall, Executive Director
510-527-4970,
Email: pemphigus@pemphigus.org

Toronto, Canada

Dan Goodwill
416-488-0453, Email: danxgail@ican.net

England

The PV Network
Flat C 26 St. Germans Rd., SE 23 1RJ,
(Enclose stamped, self-addressed envelope)

Rome, Italy

Anna Lisa Riccardi
Email: alz46@yahoo.it

Philippines

Dr. Benjamin Bince
Jose Reyes Memorial Medical Center
(632) 711-6740; Email: bbin@runbox.com

Online

www.pemphigus.org/support.html

Website

www.pemphigus.org
webmaster@pemphigus.org



MEDICAL NEWS

PEMPHIGUS: An Acronym for a Disease with Multiple Causes

Sarah Brenner, MD, Jacob Mashiah, MD, Einat Tamir, MD, Ilan Goldberg, MD and Yonit Wohl, MD

Department of Dermatology, Tel Aviv Sourasky Medical Center, and Sackler Faculty of Medicine, Tel Aviv University, Israel

Pemphigus is generally considered to stem from a genetic predisposition to the disease triggered and/or aggravated by one or more external factors. An acronym has been suggested from the name of the disease, PEMPHIGUS, to encompass those factors:

PE . . . PEsticides
M . . . Malignancy
P Pharmaceuticals
H Hormones
I Infectious agents
G Gastronomy
U UV radiation
S Stress

PEsticides

Gardening materials and pesticides are a major group of agents implicated in the development of the disease. The medical literature documents numerous cases provoked by pesticides all over the world. Organochlorine pesticides, and organophosphates, a new generation of pesticides, have been tied to the disease.

How pesticides work on the skin is unclear. It is speculated that the immune system is activated via contact or systemic exposure, resulting in the generation of autoantibodies targeting desmosomal antigens. Interestingly, in most of the reported cases the patients had a first-time, long-duration exposure to the offending substance, and developed the disease only after a massive additional exposure, resembling the induction and elicitation phases of allergic contact dermatitis.

Malignancy

Pemphigus has been associated with malignant processes, mainly hematolymphoproliferative diseases such as Hodgkin's lymphoma, chronic lymphocytic leukemia, Castelman's disease, and others. These constitute a specific clinicopathological variant called paraneoplastic pemphigus. A few reports on cases of pemphigus associated with malignant diseases that did not meet the above criteria raised the possibility of simple co-existence. In both events, the physician

should perform a malignancy-directed work-up on a pemphigus patient.

Pharmaceuticals

Drugs reported to induce pemphigus are divided into three main groups according to their chemical structure: drugs containing a sulfhydryl radical such as penicillamine; phenols such as rifampin, levodopa and aspirin; and nonthiol nonphenol drugs, such as calcium channel blockers, angiotensin converting enzyme inhibitors, NSAIDS, dipyrone, and glibenclamide.

Again, speculated mechanisms are chemical insult and immune system activation by a complicated mechanism involving diverse molecules (autoantibodies, cytokines). Calcium channel blockers are emphasized in view of the fact that the calcium ion is critical to maintaining an intact epithelium.

Hormones

Pregnancy is closely related to autoimmune diseases and thus to immunoblistering diseases, an association seen in the aggravation of pemphigus vulgaris during pregnancy, and pregnancy- or postnatally-induced herpes gestationis and neonatal pemphigus. These diseases are attributed to the passage of pathogenic autoantibodies via the placenta that target different placental antigens or skin antigens in the newborn. The role of sex hormones, mainly estrogen, in the pathogenesis of pemphigus has not yet been established.

Infection

Different infectious agents and immunizations can induce or exacerbate pemphigus, mainly by activating the cellular immune system. The most frequently incriminated infectious agents are the viruses of the herpetoviridae family, namely herpes simplex, EBV, CMV, and even HH8.

Despite the confusing clinical similarities of viral diseases and pemphigus, and because of the different outcomes of the two conditions, it is important to diagnose viral infection in a pemphigus patient and initiate early antiviral therapy, often as an adjunct to immunosuppressive therapy. Viral isolation remains the most reliable laboratory means for viral diagnosis, followed by molecular biology techniques, which are more sensitive but less reliable and indicated only in cases in which the results of the former are not conclusive.

In addition, bacteria such as coagulase positive staph aureus are capable of inducing pemphigus. Gram negative bacteria and even Actinomyces have been cultured in patients before the pemphigus becomes manifest, and were therefore described as its possible triggers.

Gastronomy

Although rarely mentioned in the literature, recent studies indicate that certain foods can induce or trigger pemphigus. Some nutritional components are chemically similar to known causative drugs, and may act in the same way. The following chemicals and related foodstuffs have been associated with pemphigus:

Phenols

Fruits: mango, bananas, potatoes, tomatoes

Nuts: pistachio, cashew

Pinenes: baked goods, smoked and grilled food, candy, chewing gum, ice cream, black pepper, cow's milk

Food additives: aspartame, sodium benzoate, tartrazine, vanillin, eugenol, caffeic acid, cinnamic acid, vitamins C & E

Tannins

Nuts: Kola, betel, walnuts

Fruits: cassava, cranberry, raspberry, blackberry, cherry, banana, apple, pear, grape skins, peach avocado

Drinks: tea, mate, fruit juice, beer, wine, liquors, water, coffee, guarana

Food additives: vanillin

Spices: ajowan, coriander, cumin, black pepper, red chillies, rosemary, garlic, ginger

Thiols

Vegetables: garlic, onion, shallot, chive, leek

Assuming that foods containing thiol, phenol, and polyphenolic compounds may contribute to pemphigus, avoidance of certain foods may lead to remission.

Ultraviolet Radiation

Pemphigus is considered a photosensitive disease, especially the superficial variant pemphigus erythematousus. Ultraviolet radiation, either occupation- or leisure-related, can induce or exacerbate the clinical manifestation. Whether the phototoxic reaction is a simple one or entails specific immune system stimulation remains to be determined.

Physical factors such as x-ray radiothera-

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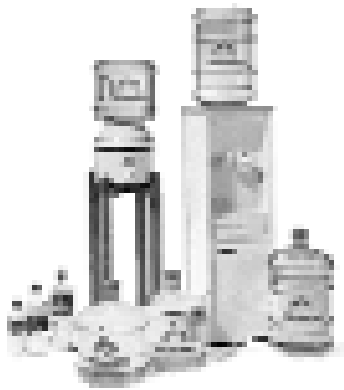
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PEMPHIGUS: AN ACRONYM, *continued from page 9*

py, burns, major surgery and cosmetic procedures have also been reported capable of inducing pemphigus.

Stress

The well-known connection between the immune and nervous systems raises the possibility that a psychoneural disorder can influence the onset and course of autoimmune disease. Several studies and case reports point to the possible contribution of emotional stress as a precipitating factor in pemphigus. Hence, avoiding emotional stress may be therapeutic in pemphigus patients, hastening the healing process and reducing or stopping the use of immunosuppressive drugs.

In summary, while the myriad causes of pemphigus complicate the differential diagnosis and course of the disease, it also points to the numerous factors that can help in its diagnosis and treatment. These factors have been documented in the studies cited here. The acronym is suggested to give clinicians a tool to pinpoint possible causes and prevent flare-ups in every newly diagnosed pemphigus patient. ☞

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FOUNDATION NEWS

Come to the Annual Meeting, Learn from the Experts, Interact with Friends, Enjoy the Day!

These images are from the last year's Doctor/Patient Meeting which took place at NYU Medical Center in New York City last August. Attendees enjoyed meeting other patients, doctors, researchers, and other friends and colleagues.

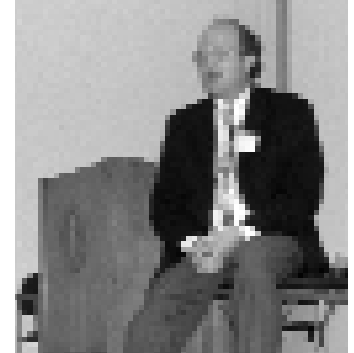


Be sure to register for this year's conference. It will certainly be an event not to be missed.



Patients getting advice from Dr. Grant Anhalt

Dr. Jean-Claude Bystryn



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