New hope for vaccine unveiled

Peptimmune presents plan, seeks NPF help

Peptide-based therapy for the treatment of pemphigus vulgaris was first reported in Issue 10 of the Pemphigus Foundation Quarterly. The researcher mentioned in that article is now coordinating his efforts with Peptimmune, a biotechnology company in the Boston area, so this important research can move forward. The following information has been written by Dr. Joyce Rico, NYU Dermatology.

Peptimmune, a biotechnology company, is very interested in developing a vaccine to treat pemphigus vulgaris, as previously reported in the National Pemphigus Foundation Quarterly newsletter. The company plans to use synthetic small molecules which resemble parts of the skin protein which causes the disease (the pemphigus antigen) to turn off the body’s immune response to the antigen.

Unlike Prednisone, Imuran, Cytosan, and other drugs currently used to treat pemphigus, a vaccine which specifically turns off the immune response to the pemphigus antigen will not suppress the body’s normal immune response and should have significantly fewer side effects.

In order to decide what parts of the pemphigus antigen trigger disease, investigators at Peptimmune are now studying the white blood cells of patients with pemphigus vulgaris. The company plans to study approximately 50 more patients with the disease. They are looking for volunteers with pemphigus vulgaris to donate 50 ml of blood, the equivalent of 4 tablespoonsful or 5 tubes. The blood will be sent to Boston, the home of the company. The white blood cells will be isolated from the blood and grown in the laboratory in the presence of different pieces of the pemphigus antigen. The response of the patient’s blood cells to the various parts of the antigen will be determined. Once the scientists determine what the important parts of the pemphigus antigen are, they will be better able to decide how to design a vaccine.

Researchers from Peptimmune, and Dr. Joyce Rico from New York University will be attending the National Pemphigus Foundation Meeting in Chicago to recruit volunteers for the blood studies. On Saturday, August 1, they will be discussing the purpose of the study, enrolling patients, and drawing blood from patients who are interested in volunteering. Volunteering to be in the study should take approximately 20 minutes. The blood drawing, like any blood drawing, is associated with brief discomfort when the needle is inserted in the vein. The amount of blood taken, 5 tubes or 4 tablespoonsful is generally very safe, however patients are encouraged to consult with their own physicians if they have any questions about their ability to participate in the study. Volunteering to have your blood drawn in Chicago does NOT mean that you will be enrolled in the vaccine study when a vaccine becomes available. Similarly, if you do not participate in the blood drawing in Chicago, you will not be excluded from the vaccine study.

If you have any questions, or would like additional information, please contact Dr. Joyce Rico, Chief, Dermatology Service, NY-VAMC, 423 East 23rd St, NY, NY 10010 (joyce.rico@med.va.gov) or Dr. Mohammed Luqman, Peptimmune, 840 Memorial Dr, Cambridge, MA 02139 (mluqman@ix.netcom.com).

New Board of Directors for NPF

With little fanfare, but significant import, the new Board of Directors for the National Pemphigus Foundation met at Johns Hopkins Medical Center in Baltimore on June 20, 1998. Remaining as President and Director is NPF founder Janet Segall, from Berkeley, California.

“The general mood of the new Board is enthusiastic and confident,” said Segall after the meeting. “We are continuing to reinforce the hard work of the previous Board, to finding new sources of revenue and continuing to grow the positive recognition we have established for the good work that we do.”

Vice President now is Jean Barish, Esq. Ms. Barish is a patent attorney with the Warner-Lambert Company, Morris Plains, New Jersey.

Dr. Grant Anhalt, whose expertise and support was crucial to the Foundation from its earliest days, continues as Vice President in charge of Scientific Affairs. Dr. Continued on page 12.
President’s Message

The politics of medicine

Recently I had conversations with physicians and researchers from around the country, especially during my participation at the annual meeting of the American Academy of Dermatology in Florida earlier this year. From these conversations, I realized that there is another aspect of medicine that sometimes take priority over the well-being of the patient. This is “the politics of medicine.”

The health care system of this country is not patient-friendly, especially for patients with rare diseases such as pemphigus. The HMO’s and Managed Care facilities care more about the “almighty dollar” than they do about patients. The UCLA School of Public Medicine released a study in June which states that between 1989 and 1996 the premiums workers paid for health coverage rose 90% to an average of $1,778.00. In this same period, wages rose only 23%.

What about those of us who are not working and can’t get insurance? How many of us have heard the phrase: “preexisting condition?” Why is health insurance tied to a job in the first place? Many (and a growing number of people) work for themselves. Many positions which were held by in-house employees are now slotted for consultants who get no benefits at all. What about those of us who lose their insurance, or have to pay such high premiums they cannot afford them?

The state will not help unless a patient is destitute. This means that the vast majority of the person’s assets, including savings, retirement accounts and life insurance, have to be liquidated, thus wiping out the hard work of a lifetime. Sometimes humanity can be lost in the shuffle and the patient ends up getting hurt.

At a recent American Autoimmune Related Diseases Association (AARD) conference in Detroit, Stephen Balch, M.D., Director of the Jacqueline McClure Lupus Center, in Atlanta, Georgia said, “the real problem with diagnosis of autoimmune diseases is that the time that a physician can spend with you (the patient) is limited, and listening to the patient is the only way to diagnose most autoimmune diseases. It may take a period of time for the diagnosis to be confirmed.” One in five Americans has an autoimmune disease.

An AMA study reported that 61% of patients felt that doctors don’t spend enough time with them. Even if one has coverage, health insurance companies will generally not subsidize physicians who need to spend more time with patients with difficult diseases.

The time it takes to simply apply for specialists in some cases may be so long that the patient begins to deteriorate. Sometimes visits to specialists are not approved by all. This forces a patient to stay with a general practitioner who might not be willing or knowledgeable enough to give even adequate treatment.

And, what about approval for drugs? Some of the drugs we need are expensive. A patient might work his or her whole life, paying his health care premiums faithfully—and get his doctor’s prescription turned down because of the cost of the drugs. It took one of our own an entire year to get approval for Fosamax. In the mean-time he lost significant bone mass, which probably reduced the quality of his life forever. Meanwhile, drug company profits are soaring to record heights.

Up and coming physicians have little incentive to learn about rare diseases. Our health care system is for young, healthy people. The business of health is “Big Business.” HMOs, insurance companies and drug companies spend millions to lobby congress. Who speaks for us?

The first project President Clinton promised after his election was to revamp the health care system. His efforts (with Hillary) failed. Congress brings up the topic on occasion and puts it down again. This cannot go on. Human beings are suffering and dying needlessly. There are better treatments out there. There are cures just waiting to be found.

We can call on doctors and researchers to redouble their efforts, but we must also speak up for ourselves. We need to become lobbyists. We need a loud, clear voice. Talk to your doctor. Write the insurance companies. Hold our politicians’ feet to the fire until they address this difficult, growing and vitally important problem. If those of us with health problems don’t speak up for ourselves, who will?

Future generations depend on us.

Janet Segall
President
Autoimmunity and your family, Researchers looking at genetics

By Sal Capo

One out of every five Americans has some kind of autoimmune disease. Put another way, that's over 50 million people. Seventy-five percent of those 50 million are women ( pemphigus is one of a few autoimmune diseases which treat the sexes equally). Autoimmune problems cause over 80 different diseases, including lupus, scleroderma, rheumatoid arthritis, multiple sclerosis, autoimmune hepatitis, and of course, pemphigus. So far none of these illnesses can be cured.

Noel Rose, M.D., Ph.D., Professor of Molecular Microbiology and Immunology and Pathology at Johns Hopkins University was quoted as saying: "This nation involves some $86 billion of its health care money in the treatment of autoimmune disease. We're talking about a major health problem in the United States. Autoimmune disease in the aggregate is right up there with cancer and heart disease as major disease problems in this country, both from the point of view of the number of people involved and the amount of our health care effort that goes into autoimmune disease."

"Despite their devastating human and economic toll, autoimmune diseases are among the least investigated, most difficult to diagnose, and physically and emotionally painful diseases that face Americans today," said Susan Wood, Ph.D., and newly appointed Acting Deputy Assistant U.S. Secretary for Women's Health, Department of Health and Human Services for the National Institutes of Health.

Stephen Katz, M.D., Ph.D., Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, stated: "Two of the hottest areas in medicine today are genetics and immunology. Advances in these areas will have a direct impact on our understanding of autoimmune. With regard to genetics, the fact that autoimmune diseases can run in families indicates that the development of these diseases has a genetic basis." Several genetic studies released recently have identified genes that may play a role in autoimmune diseases.

Towards that end, one study by the Yale University School of Medicine and St. Mary's Hospital in Connecticut isolated an antibody which is a "common thread" in families. This antibody, known as the antiphospholipid antibody (APL), is an "auto-antibody" protein produced by the body to attack itself. When APL levels are too high disease occurs. If at least one family member suffers from an autoimmune disorder associated with high levels of APL, others did also.

Twenty-three family members, 87 blood relatives, 18 spouses and 37 controls were included in the Yale and St. Mary's study. Auto-antibodies were found in almost 60% of the blood relatives. Only one spouse showed the same. One third had APL antibodies, while another 37% had other auto-antibodies. The control subjects showed no positive results. Eight relatives were found to have lupus or lupus-like syndrome, two had suffered premature stroke, and three had recurrent fetal loss.

Thomas Greco, M.D., assistant clinical professor of medicine at the Yale University School of Medicine said "While the study is relatively small, it is supported by other previous studies that suggest APL antibodies may actually be genetically transmitted from family member to family member, from generation to generation. More important, the APL antibody may be associated with one disease process in one family member and yet another disease process in another family member."

Independently research by Duke University scientists into the genetic patterns of 12 unrelated families with APL found the possibility that a single inherited genetic defect may be at fault. These findings support Dr. Greco's research, and in fact, Dr. Greco has begun a study with Duke University researchers to define the genetic defect which causes these diseases. This would put Dr. Greco on the evening news and be a major step in medicine for mankind.

Recent data presented by French researchers shows families with APL antibodies had diseases related to these proteins, as well as many other immune system troubles such as rheumatoid arthritis, systemic lupus erythematosus, and multiple sclerosis, among others.

Dr. Greco pointed out that while these proteins are seen in only about one or two percent of the population of patients nationwide, in affected families the rate may be as high as 50%.

"If an APL inheritance pattern can be firmly established in future studies, the good news is that we may be able to prevent premature stroke, heart attack, recurrent miscarriage and the other APL-associated diseases by performing simple and inexpensive tests and taking more thorough family histories," Dr. Greco predicted.

"It may be premature to say, but APL may end up being one of the common threads that ties together all of the seemingly unrelated 80 known autoimmune diseases," said Virginia Ladd, president of the American Autoimmune Related Diseases Association (AARDA). "If it turns out that APL is a common factor in autoimmune diseases, then the next step for researchers is to begin looking for an autoimmune gene."

Unlock one autoimmune disease and perhaps they all open. These are very exciting times in research labs. Many are involved and progress is made daily. Stay tuned.
San Francisco

No meeting was held in time for this edition.

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Los Angeles

On May 17, the special guest speaker was Dr. Paul Levens, UCLA Dermatology. Dr. Levens presented slides concerning how easy it is to misdiagnose pemphigus. He then answered questions from the group.

The Group recommended to President Segall that Lee Heins, be named as Fund-raising Chairperson for the West Coast on the NPF Board of Directors.

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Toronto

By Dan Goodwill

The Toronto Support Group held its most recent meeting on Sunday, June 14. Thirteen people attended the meeting. For the first hour of the meeting, Robin Silverstein, a dietitian, led a discussion on pemphigus and diet. Prior to the meeting she reviewed the "Coping with Prednisone" and "Blood Type Diet" books.

During the course of the discussion, Robin outlined the importance of eating foods from the five major food groups identified on Canada's Health Food Guide. Everyone should have five to 12 servings of grain products, five to 10 servings of fruits and vegetables, two to four servings of dairy products and two to three servings of meat and/or fish and/or alternatives on a daily basis.

She also stressed the importance of eating a variety of foods in each category. While supplements can be helpful, one should try to get one’s nutrients from the food one eats and not just from supplements alone. Each food product provides a range of nutrients. The omega-3 fatty acids in fish such as salmon are also important. Robin indicated that there is no body of research to support the “Blood Type Diet.”

During the second hour of the meeting we reviewed the current state of health of each of the Support Group members, new and old. The Group also expressed a willingness to approach each of their dermatologists to determine if they would be willing to hand out the Foundation pamphlets to newly diagnosed pemphigus patients.

The Group also discussed plans to conduct a mailing to all of the Ontario based dermatologists. The mailing would be signed by one of the province’s leading dermatologists.

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New York

By Joan DeLucie

On May 14, 1998 the New York Support Group welcomed Maryann Driscoll, Ph.D., as our guest speaker for the evening. Dr. Driscoll is a licensed Psychologist and Educational Consultant and an associate professor at Touro College School of Health Sciences Physical Therapy Program. The topic for the evening was "Coping with an Autoimmune Disease: Strategies for Keeping a Grip." Dr. Driscoll started the discussion by speaking about how keeping a grip with humor and knowledge can have a positive impact on one's life and how support groups can extend and enhance our lives. She also discussed ways to not make our condition worse, the role anger plays in our lives, and emphasized the importance of being aware of the "should" word.

She continued her discussion with the three Cs: challenge, control and commitment. She recommended that we look at adverse conditions in our lives as a challenge and use the problem-solving approach to help us live longer and stress harder. She discussed how we can "get into balance" by making choices that help us modify our lives so we can ultimately maximize our lives.

Dr. Driscoll also spoke about how we can age better and live longer if we have a commitment to something and how critically important commitment is for keeping a grip. She further pointed out how the human connection helps us live longer.

Some interesting points Dr. Driscoll made were that we should learn to pick our battles, not make unfair comparisons and be aware of some of the statements we make to ourselves. She emphasized that overreacting to a problem can increase wear and tear on an individual’s body as well as being unfavorable for the receiver.

In addition to our guest speaker, the group welcomed new members; Anthony Coletti, Esther Laks, Larry Mishkind and Marcia Pepper. The upcoming Chicago trip was also briefly discussed.

Our next meeting is planned for September. The guest speaker is a pemphigus patient whose disease has been in remission for several years. He will be sharing his treatment therapy experiences with us. Check your mailboxes for announcements in mid-August. My best wishes to all members, family and friends for a pleasant, safe and healthy summer. I look forward to seeing you at the September meeting.

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Groups

A crowd of 50 listened to the presentation by Dr. Anhalt, Dr. Rico and Janet Segal at the meeting at Johns Hopkins in conjunction with the Baltimore Support Group's first meeting.

Baltimore

By Erica Byrne

On Saturday, June 20, more than 50 people gathered at Johns Hopkins Hospital in Baltimore, Maryland in an event organized by Dr. Anhalt and the NPF. (photo above). Janet Segall spoke about her personal experiences with pemphigus, and the conception of the NPF. She also discussed future aspirations for the Foundation, and the continued need for funding. Dr. Anhalt then shared some of his knowledge about pemphigus, including the way in which it affects the body, and current treatment regimes.

He also spent a considerable amount of time answering specific questions about medications, side effects, and research, among other topics. This get-together lasted the majority of the day, and was a very successful way in which to share information.

Shortly after, several people remained for the first Baltimore Support Group meeting. This was attended by 10 people, including five with pemphigus.

As this was the first meeting, introductions were made, and personal experiences were shared about dealing with pemphigus. In addition, suggestions were given for future topics of discussion, as well as speakers.

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Midwest

By Arlene Strauss

The Midwest Chapter is gearing up for the Chicago get together. The weather has been great here, so I hope it keeps up for everyone while you are in our beautiful city. Don’t forget your cameras. There are some terrific sites to see in Chi Town.

I’m supplying Janet with activity information for anyone who is interested in doing any site-seeing while they are in town. Looking forward to seeing everyone who is going to attend.

See you soon.

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Philadelphia

By Jim Marple

Our Support Group met on June 19, 1998 and was pleased to have Jennifer Torshisk, Physical Therapist, talk about the importance of physical exercise for pemphigus patients. Ms. Torshisk stressed the importance of strengthening and weight bearing exercises to maintain bone and muscle strength for those taking prednisone. She also instructed us on aerobic exercise and various stretches to maintain flexibility.

Contact: Barbara Sipe
Phone: 215-662-6440

The NPF Website

The NPF website is now located at www.pemphigus.org. Please let us know how we might improve our site.

Links of interest

American Academy of Dermatology
930 North Meacham Rd.
P.O. Box 4014
Schaumburg, IL 60168-4014
Phone: 888-462-4ERM
www.aad.org

National Organization of Rare Diseases
P.O. Box 8923
Fairfield, CT 06812-8923
Phone: 800-999-6673
www.pcnetwork.org/orphan

National Osteoporosis Foundation
c/o AMA
515 North State Street
Chicago, IL 60610
Phone: 312-464-5110
www.nof.org

Online support

Not part of the NPF, but open to all, an online support group is available. Email majordomo@lists.cycervar.com. In the body of the message write: subscribe pemphigus_support. If you have any questions contact the NPF.
Iron Man, Iron Heart

By Michael J. Main

I remember like it was yesterday, fall of 1990, approaching my 31st birthday and our 5th wedding anniversary, holding my wife and she holding me. The comfort of our arms around each other, tears ran down my face. It was the first time we shared such an emotional release. Men simply do not show emotion, even in times of challenge such as this - being diagnosed with a "potentially fatal and debilitating disease."

July 1990, just three months earlier, blisters began appearing in my mouth and right eye. A family practice physician assured me the blisters in my mouth were mucous cysts and were nothing to worry about. Later, three more family practice doctors, working as a team, prescribed antibiotics and referred me to an ophthalmologist for the eye. The ophthalmologist promptly diagnosed herpes and proudly brought in an intern to witness my symptoms.

After both the antibiotics and the ophthalmologist's Rx failed to improve the increasingly painful lesions in my mouth and eye, an internal medicine specialist and periodontist referred me to an oral surgeon. The oral surgeon put me on an elimination diet of brown rice to test for food allergies. As if I hadn't lost enough weight already, my weight fell to a rail-thin 170 lbs on my 6'2" frame. The elimination diet did not improve the still worsening sores.

Finally, a biopsy was performed and the oral surgeon diagnosed pemphigus vulgaris. It was described to me at the time as "a potentially fatal autoimmune disease, which could be controlled by corticosteroids that can also be debilitating."

He assured me that my normally very busy and athletic life-style would be curtailed by the disease and its treatment. Indeed, he was very specific in predicting I would never race in triathlons (my passionate hobby) again, let alone compete in my dream event: the Ironman.

Treatment went like this: five years of up to 100 mg of Prednisone daily and five mg of Methotrexate four days per week. I flared three times while tapering off the medication (each time going back up to 100 or 80 mgs to begin the taper again). Since 1995, I have been mostly free of medication, other than one flare last year which put me back on Prednisone for five months. Based solely on personal discretion, I still use temovate gel on my gums when needed. I have tried lots of different alternative approaches to the disease.

Acupuncture eliminated all my lesions for the first time since my original diagnosis. Unfortunately, cost and the acupuncturists' inability to maintain success in treatment caused me to stop. I know all of us are different, yet if you asked, I think meditation on the thought of "pure love" - in retrospect, the feeling of crying into my wife's arms and sharing my vulnerability while being totally loved and accepted is my greatest medicine - which brings this article to a peculiar twist.

For five years, I fought the disease. In fact, I fought quite a bit - my mortality, my marriage, my job and the reality of my circumstance. In 1993, I even did an Ironman triathlon: 2.4 mile swim, 112 mile bike, and 26.2 mile run. I proved the doctors were wrong about me, that PV was not going to limit me any more than any other event in my life.

Peace, inner peace, on the other hand has crept into my life since those turbulent days. Family, a loving and connected relationship with my wife Esther, my three young sons, nature, and connection with others all receive significant focus from me. The pursuit of worthy goals, like higher education, economic success, and athletic accomplishment still remain important, but for different reasons. When a good friend in California invited me to compete in another Ironman this summer, the answer was yes.

Forgive the cliche, but while lovingly connected we still need to seize the day: carpe diem. Only this time the Ironman would be for more than proving the doctors wrong.

The "Ironman for Charity" was born! You see, everyone I have an opportunity to speak with, both personally and professionally, I tell the story of how the diagnosis of pemphigus was made and how doctors misdiagnosed the symptoms for too long. They hear about how fortunate I am compared to others who have much more serious symptoms. They also hear about what a tremendous job the National Pemphigus Foundation is doing to educate others and provide a catalyst to support groups internationally.

Then they hear that the Vineeman "Ironman" is being run for donations to the Foundation. Initial results from the campaign show that 92% of the people solicited will agree to sponsor me in the triathlon.

This event will raise thousands of dollars for the Foundation. If I can swim 2.4 miles, bike 112 and run 26.2 in one day and be healthier for it, then certainly the goodness in people's hearts will guide them to give to such a worthy cause. Life is after all a gift. It is our job to live it to the fullest. Feel free to call me at 630-579-0134 or write me at EK MJ Main @aol.com.

To date Mr. Main has raised $7,837 for the Pemphigus Foundation and the YMCA combined. The Naperville Metro, The Naperville Sun, The Daily Herald and The Chicago Tribune are newspapers running his story complete with photos. Pemphigus and the Foundation are prominently mentioned in all the articles. His next event is the Vineeman "Ironman" Triathlon, July 25, in Santa Rosa, California.
The test for pemphigus, part one

In 1965 Dr. Ernst Beutner and his team discovered the pemphigus antibodies which cause the disease. Because blood tests for pemphigus play a key role in the diagnosis, management and basic studies of the disease, he and his associates, Dr. Fang and Dr. Sofat continue to provide non-profit quality control programs for them.

By Ernest H. Beutner, Ph.D.
Prof. of Microbiology and Dermatology
University of Buffalo School of Medicine
and Biomedical Sciences
Buffalo, New York

Patients with pemphigus may benefit by working with their doctors to gain a better understanding of the tests used to detect and control the disease, in some situations. Three groups of tests can help doctors diagnose pemphigus; one of these can also help to control the disease in some situations. Two groups use skin or oral tissue samples, one for light microscopy and one for direct immunofluorescence. A third group uses blood tests for the pemphigus antibodies that cause the disease; these fluctuate with disease activity. Many doctors use all three methods to check all diagnoses of pemphigus; each test gives different types of information.

Part One of this series summarizes what these blood tests can show and lists the two evaluation programs that labs can use to verify the procedures. In running one of these programs we find: a) most labs that check their tests do them well, b) some need to improve and c) some labs fail to check the quality of the blood tests they do. First we review what these tests can tell us about the diagnosis and treatment responses, if they are done correctly.

Diagnosis: Blood tests for pemphigus serve as highly sensitive diagnostic tests. The “titer” of these tests tell us the amount of antibody; low titers of 10, 20 or 40 need to be interpreted with caution. Almost all patients with active pemphigus give positive blood tests, usually with titers of 80 or more. If two repeat tests in an active phase of the disease give negative results, then three possibilities need to be considered.

1) False negative tests occur if they are not done correctly.
2) The patient may not have pemphigus; that is, the diagnosis may be wrong.
3) Reaction of blood sample may cause special problems; labs can usually see and explain such problems.

Selected terms

Amino acids: The organic building blocks which form proteins. When proteins are digested, amino acids are left. Thirteen of the approximately 20 amino acids humans need for a healthy life are manufactured in the body. The others must be attained through food, mainly animal products such as meat and dairy.

Antibody: A protein manufactured to overcome substances, called antigens, which the immune system considers toxic.

Antigen: Substances which are considered harmful to the body by the immune system. This, in turn, causes the production of antibodies to combat the danger. Antigens either come from the environment (chemicals), or are formed in the body (bacteria or viruses).

Protein: A complex organic compound which is made up of amino acids which contain carbon, hydrogen, oxygen and nitrogen. The nitrogen element differentiates proteins from carbohydrates and fats. Protein is the main building block of all human cells. This includes muscles and organs such as the skin.

Titer: This refers to the amount of antibodies circulating in the blood stream. Titers can sometimes be used to measure the progress of a disease. In the case of pemphigus, however the titer count may not correlate with disease activity. At times even without detectable levels of titers, the disease can be very active.

The selection of the type of blood tests depends, in part, on the type of pemphigus. Mucosal pemphigus can cause lesions of the mouth, nose, esophagus or genital mucous membranes [and] often also affects the skin. These types include pemphigus vulgaris, pemphigus vegetans and paraneo-plastic pemphigus. To perform the blood tests properly, they need to be carried out on thin sections of monkey esophagus. Pemphigus of only the skin is usually less severe.

With pemphigus foliaceus, pemphigus erythematous and pemphigus herpetiformis cases, added blood tests are often needed, since antibodies of these cases may not react with monkey esophagus; but guinea pig esophagus or human skin sections give positive blood tests in about all active cases.

Evaluations of treatment responses: Titers of blood tests go down when treatment is successful. If titer becomes negative, it indicates that the disease may be under control. Thus, some doctors ask for repeat blood tests to aid in checking on treatment responses. Labs that do such repeat tests need to keep the previous blood serum on file to compare with the new one.

Checks on blood tests for pemphigus: The reliability of these tests should be checked annually by all labs that do them. Two voluntary proficiency programs give labs certificates of participation, notably:

1) The Ernest Wittecky Center for Immunology of the University at Buffalo and Beutner Laboratories; P.O. Box 26, Buffalo, NY 14215-0026; Phone: 716-838-0549. All labs can use this program.

2) The Mayo Clinic: Attention, Dr. Arnold Schroeter; Department of Dermatology; Mayo Clinic; Rochester, MN 55905; Phone: 507-284-6891. Only dermatopathologists (ASDP members) can use this program.

You may wish to show this to your physician. Part Two of this series in the next newsletter will give tips on how to work with your physician to check on the reliability of blood tests they order.
Questions and Answers

DISCLAIMER: The information offered here is not intended as medical advice. Pemphigus and the drugs used to treat pemphigus affect everyone in different ways. Reasonable people will discuss changes in their treatments with qualified physicians.

Q Should I avoid exposure to the sun?
A The experts say yes. The Department of Dermatology, Nara Medical University, (Japan) did a small study in 1996 on the effects of sun and ultraviolet light (such as found on cloudy days and tanning salons) and reported that such exposure exacerbated activity in both pemphigus vulgaris and pemphigus foliaceus. This was preceded by a 1995 article in the International Journal of Dermatology about a study in Greece which showed “a strong correlation between climatologic data (sun exposure and air temperature) and pemphigus (vulgaris) activity.”

However, a non-scientific sampling of the pemphigus online support group suggests that this is not the rule. Some effects which were reported in regard to exposure to sunshine included an increase in fatigue, itchiness or irritability.

Even if the sun does not directly cause flares, staying out of the sun is probably a good idea, because some of the medicines taken to fight pemphigus can cause an increase in sun sensitivity. These drugs include Prednisone, methotrexate and tetracycline. The damage the sun does is not always immediately evident. Dermatologists universally encourage even healthy persons to use sunscreen, avoid long periods in direct sun, especially midday; some even prefer wide-brimmed hats and closely woven clothing. While you probably do not have to banish yourself to dark closets, common sense and caution are warranted.

Speaking of sun screens, the Army studied the effects of using bug repellent (DEET) and sunscreen (Copertone Sport SPF 15) to find that the repellent reduces the sun-blocking effects of the sunscreen by up an average of 33.5%. The sooner the repellent was applied after the sunscreen, the less the sunscreen worked.

Q I can’t remember what I read, it doesn’t predispose cause memory loss?
A It may. Long term corticosteroid use is suspected to diminish the memory in some, under certain conditions. That’s the bad news. The good news is that you may be able to offset a loss of memory.

University of Berne (Switzerland) researchers studied the slow loss of memory performance in people 65 to 94 years of age, correlated to the participants’ blood levels of vitamin C, vitamin E and beta carotene. They compared their results to a study done in 1991. The results were strikingly similar.

The researchers concluded that “the results of the memory tests showed that among participants aged 65 years or older a high level of vitamin C and beta-carotene is closely related to better memory performance (free recall, recognition, and vocabulary). This correlation held true even after adjusting for other variables which might affect memory, such as blood pressure, cholesterol, ferritin, age, gender, and educational level. The researchers found no correlation between the blood level of vitamin E and memory performance and no additive effects of the antioxidants. They conclude that antioxidants play an important role in the prevention of cognitive impairments related to brain aging.”

Further, Dr. Jason Mehta of the University of Florida released a study in 1997 in which a questionnaire was sent to 450 members of the American College of Cardiology. Forty-four percent of the 181 responding reported supplementing their diet with antioxidants. The most common antioxidant used was vitamin E (taken by 39%), the most common dosage was 400 IU/day, Vitamin C (500 mg/day) was taken by 33% of the respondents and beta-carotene (20,000 IU/day) was taken by 19%. Forty-two percent took aspirin daily as prevention against coronary heart disease, usually 325 mg/day. Twenty-eight percent of the respondents took both antioxidants and aspirin.

Dr. Mehta found it interesting that "although 44% of all respondents used antioxidants themselves, a somewhat smaller percentage (37%) recommended antioxidants routinely to their patients with coronary artery disease.”

Q What is thrush and how can I prevent it?
A One of the many microorganisms normally found in the mouth is the fungus candida albicans, which is the same fungus associated with vaginal yeast. The overgrowth of candida, commonly called "oral thrush," is caused by reduced natural resistance from illness, stress and long-term use of corticosteroids or medications such as antibiotics or birth control pills. Small children, pregnant women and the elderly are also at elevated risks.

Oral thrush is identified by creamy-white, slightly-raised lesions on the tongue or inner cheeks which look something like cottage cheese. If lesions are disturbed they may show a reddened area underneath. Light bleeding is possible and it can be painful but is rarely serious.

Prescriptions of highly effective antifungal medications such as nystatin, clotrimazole, miconazole, and others are given for seven to 10 days. Good oral hygiene is important in controlling thrush. Overuse of mouthwash and sprays may upset the balance of microorganisms in the mouth and should be avoided. Warm salt water rinses (1/2 teaspoon of salt in a cup of water) are often soothing.

Q If steroids are used to reduce the immune response what dangers do I run regarding infections?
A In general, steroids do not increase the chance of infection, such as a bad cold. Exceptions however, can be serious. Certain viruses, including varicella (chickenpox) and other herpes viruses, deserve special mention.

According to the book "Coping with Prednisone" by Zukerman and Ingelfinger, "Chickenpox can be particularly severe in individuals taking high-dose steroids, and fatalities can occur. While there is now a vaccine (Varivax) against chickenpox you cannot be immunized with it while you are on high-dose steroids. If you are susceptible to chickenpox and you are exposed, you should get a shot of a special gamma globulin (varicella immune globulin, or V-ZIG) within 72 hours. If, in spite of being given gamma globulin, chickenpox develops, antiviral medicine such as acyclovir or ganciclovir can be lifesaving. It is important to discuss the varicella issue with your doctor before you start steroid treatment.

Those on steroids are also prone to get herpes zoster (shingles) after having chickenpox.
Smoothies: cool, easy and healthy

Cold, refreshing and nutritious, smoothies are a great way to soothe a sore throat or just enjoy a warm summer day.

Smoothies shops are appearing across the nation as frequently as coffee stands. Recipes abound in books, on the internet or in newspapers and magazines.

But we think beauty is on the lips of the thirsty. We suggest experimenting to find the exact ingredients and combinations of ingredients which best bring a frothy moustached smile to your mug.

Here we present a pitifully small sample to get you started. All you need is a blender and an imagination (We sparked our imagination by visiting our local smoothie shops and studying the combos on their menus). Enjoy!

Oh, and check with your nutritionist about your individual requirements. Bananas for example have the potassium for those on Prednisone, but they are also high in calories we may want to limit.

Basic ingredients and proportions:
- 1 frozen banana (best if cut into one-inch chunks, then frozen)
- 1-3 ice cubes
- 1/2 - 1 cup of fruit
- 1/4 to 1/2 cup of nonfat yogurt or ice milk*
- (*For an extra-nutritious smoothie, use 1/4 to 1/2 cup of orange juice or soy milk instead)
- Add ingredients in a blender and blend until smooth. It’s that easy.

Try these suggestions or make up your own variations:

One cup of any of these easy-to-find fruits: strawberries (hulled), peaches (fresh or canned), apple slices (or juice).

Not-so-easy to find, but worth the effort, are these exotic combos:
- Tangerine and mango nectars
- Mango, papaya, honeydew and cantaloupe
- Peach yogurt with pineapple, orange and banana juice (available premixed in juice section of your local market)
- Kiwi, strawberries and pineapple juice
- Apricots, mango and lemonade
- Papaya, raspberries and any juice

Feeling festive or daring? Add cinnamon and/or nutmeg, cloves, ginger or vanilla. Protein powder and wheat-germ work also.

Don’t forget your veggies! If you have a juicer try this one:

Juice from 5 or 6 carrots (2 cups)
1 1/2 to 2 cups of yogurt (plain, vanilla or flavored)
1 banana, fresh or frozen
Several mint leaves

Hot smoothies?!!
Those having trouble eating regular food can use a blender to make adult versions of baby food. We hear the home-made lasagne is great.

Correction

Last quarter’s issue was erroneously labeled as Issue 12, when it should have been Issue 13.

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The National Pemphigus Foundation

There's no better way to stay informed. Period.
Choosing foods by blood type

By Steve Shapiro

I’ve now been choosing my foods according to the blood type theory for one year, and it has been a very dramatic and remarkable year. My health and vigor have returned, and while I still have some signs of disease activity, the symptoms are diminishing constantly. Many questions have been fielded about this method of food choice.

These are the most representative:

How long will it take to see results? That depends on where you are starting from. Some people living with other illnesses as serious as pemphigus report that they begin to feel better and show signs of disease remission within two weeks. Usually, it takes about two months, and in some cases, it can be as long as six months for notable results to occur.

How are foods determined to be beneficial? The primary indicators are: The food does not agglutinate that blood type and the digestive tract shows a distinct ability to digest the food.

How are foods determined to be avoided? The opposite applies: The food reacts adversely with the blood type and it can not be effectively digested.

What about foods that are not on the list? If a food is not on the list, it should be avoided.

What about garlic, onions and leeks? The study conducted showing that garlic and onions may trigger pemphigus was not conclusive. The leek connection is based on one person’s experience. If you believe that you are reacting to these vegetables, by all means avoid them.

How do I get started? There are two methods of getting started. For the ‘Cold Turkey’ method, throw out or give away avoid foods and replace them immediately with neutrals/beneficial foods. The other choice is to eat them and phase them out by replacing with neutral/beneficial foods.

Can I stop taking my medication? NO! The medications many of us take are extremely addictive, and have to be withdrawn slowly, titrated to your symptoms. Do not stop taking them without consultation with the prescribing physician or other knowledgeable practitioner.

I thought pemphigus was genetic? While it has been found that people with some autoimmune diseases have a genetic or familial predisposition, it is not conclusive. Furthermore, there is no stronger example of genetic inheritance than blood type. Wrong foods plus wrong blood type equals wrong agglutinins, yielding increased inflammatory response. The result, in our case, is pemphigus. Choosing foods to decrease the inflammatory response will stop the reactions before they start.

Why is a food listed as beneficial/avoid and an extract of the food is listed oppositely? Processing may chemically alter the structure of the food, concentrate a beneficial/avoid component, or isolate/remove a beneficial/avoid component.

I don’t know what some of these foods are. Start to shop at natural health food stores and natural foods sections in supermarkets. Don’t be embarrassed to ask lots of questions. If there is no store near you, or they do not stock the products you want, check catalogs and the Internet. Catalogs are frequently advertised in magazines geared for the healthy eater, such as Vegetarian Times, New Age Journal, etc. Ezekiel Bread is a brand name of a commercially available bread, sold in health food stores, that is made from 100% sprouted grains and beans. Always choose organically grown food if it is available.

How long will I have to be on this diet? Choosing foods this way represents a lifelong commitment. It is always up to you to decide what foods go into your mouth, and you are always free to eat whatever you choose. Many people report having adverse reactions to avoid foods after choosing beneficial & neutrals for a six month period. This is our bodies natural way to tell us that these foods are not healthy, and you will naturally start to avoid them. I don’t think of it as a diet in the traditional sense, as one is free to eat as much as you want whenever you want. There is no calorie counting.

Is there anything else I should know? Yes, this is a new and emerging science, and we expect to keep learning. If you are not seeing results after six months of choosing your foods this way, please contact me for additional information on modifications that can be made to your food choices.

I congratulate everyone who has made a conscious decision to do something today in order to live a pemphigus-free tomorrow. If you would like a formatted list of foods for your blood type, please send me two stamps and your blood type.

This article is based on information found in the book “Eat Right 4 Your Type” by Dr. Peter D’Adamo and the website http://www.dadamo.com.

Editor’s note: Mr. Shapiro is not a licensed physician. His views are his own and provided here for information only. Discuss your individual medical situation with your physician. The National Pemphigus Foundation is not connected with Dr. Peter D’Adamo.

The Foundation regrets to announce that due to an increasingly busy schedule, Mr. Shapiro will no longer be able to contribute to this newsletter on a regular basis. We thank him for his generous past contributions and wish him good fortune in his other endeavors.
The volunteers listed here are available to those who have questions or just want to talk about subjects connected to pemphigus. If you would like to volunteer, contact the National Pemphigus Foundation at the address on page two.

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Experts and excitement in Chicago

Anyone and everyone concerned with pemphigus is invited to the first national meeting of the NPF on Saturday, August 1, 1998. The milestone will be celebrated at the Hyatt Regency in Chicago, Illinois.

A full day of activities are scheduled. Highlights include a talk by Dr. Grant Anhalt, Vice President of Scientific Affairs for the NPF and Acting Head of Dermatology at Johns Hopkins, and Dr. Sarah Brenner of Israel, who will discuss how diet affects pemphigus. Other distinguished experts on pemphigus will also make presentations.

Morning events will include a "Get Acquainted" brunch. Hors d'oeuvres and a cash bar are planned for later in the day before dinner. The price for the brunch alone is $20.00, the dinner alone is $35.00 and both meals are $50.00. Deposits must arrive at the NPF headquarters before July 20, or tickets will be sold at the door for those who have called to reserve a seat in advance. This is to facilitate a correct head-count. Those who have already sent a deposit will be credited in Chicago. Mail checks to cover the meals desired to the National Pemphigus Foundation, P.O. Box 9606, Berkeley, CA 94709-0606.

Look for additional details in a flyer sent with this issue of the Quarterly.

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