NIH wants office for autoimmune disease

By Sal Capo
Communications Director

A bill to establish an “Office of Autoimmune Disease” was introduced in the U.S. Senate in November by Delaware Senator Joseph Biden.

Senator Joseph Biden

Biden’s intention is for the director of the proposed office to develop an agenda for conducting and supporting research on autoimmune diseases using the national research institutes.

The agenda provides for a “broad range of research and education activities relating to biomedical, psychosocial, and rehabilitative issues, including studies of the disproportionate impact of such diseases on women.”

The National Coalition of Autoimmune Patient Groups (NACPG), headquartered in Eastpoint Michigan, reports 19 cosponsors to the bill. They are requesting that member organizations initiate a letter writing campaign to members of the HELP Committee to encourage passage of this legislation known as S1897.

NACPG includes the American Autoimmune Related Diseases Association (AARDA), the Arthritis Foundation, Lupus Foundation of America, the NPF and others.

An allocation of $950,000 for fiscal year 2000 would be authorized, along with “such sums as may be necessary for each of fiscal years 2001 and 2002.”

The bill, S1897, is presently in the Health, Education, Labor and Pensions Committee. The title of the bill is “NIH Office of Autoimmune Diseases Act of 1999.” If the committee passes the bill it will proceed to the floor of the Senate for a vote, then to the House, before the President signs it into law.

Republicans on the committee include: James Jeffords (VT), Judd Gregg (NH), William Frist (TN), Mike DeWine (OH), Mile Enzi (WY), Tim Hutchinson (AR), Susan Collins (ME), Sam Brownback (KS), Charles Hagel (NE), Jeff Sessions (AL). The Democrats are: Edward Kennedy (MA), Christopher Dodd (CT), Tom Harkin (IA), Barbara Mikulski (MD), Jeff Bingaman (NM), Patty Murray (WA), Jack Reed (RI).

Committee lists priorities

The NIH Autoimmune Coordinating Committee held a meeting December 2, 1999 to discuss collaborative projects and opportunities that will be funded with a $30 million initiative.

AARDA (American Autoimmune Related Diseases Association) made a presentation on behalf of NACPG that incorporated suggestion from its members.

“Part of the presentation focused on the need for more attention from lesser known autoimmune diseases,” said Virginia Ladd, President of NACPG.

The groups priorities were narrowed to:

1. Autoimmune disease registry (including rare diseases),
2. Antiphospholipid as a common thread in autoimmune diseases,
3. Multi-discipline autoimmune diagnostics, and
4. Epidemiological studies, genetic interrelationships, environmental triggers, nutritional effects, stress, drug-induced disease.

Dr. James Sciuuba joins Board

Dr. James Sciuuba, who assumed the Directorship of Dental and Oral Medicine at Johns Hopkins Medical Center in December 1999, joined the Medical Advisor Board of the National Pemphigus Foundation in January 2000. Dr. Sciuuba also spoke at the second annual NPF Conference held in New York last July.

Nutrition

One of the latest media darlings is the soybean. Should you try them too? See page 10

Stress makes everything worse

Find out what you can do to reduce or avoid it. See page 16

Group reports

See page 12

Contents
1. The view from here
2. Anhalt on blisters
3. Now you know
4. 6-7. Nutrition: soybeans
5. 8-10. Social Security
6. 11. Heart2Heart
7. 12-13. Support groups
9. 16. BodyWorks
Our first and foremost objective is to bring information and support—and we are doing that

With many promising new scientific discoveries, I hope this new year, century and millennium bring all of us good health; a life without pemphigus, pemphigoid or anything else that might hinder our efforts to become the best we can.

At the meeting in Washington last year, one of the representatives of another foundation came up to me and said she was amazed at how much we accomplished. She said, “You have done more in four years than we have in 20!” With the help and support of a lot of wonderful, committed and talented people, we have begun to carry out our goals and objectives. Our first and foremost objective is to bring information and support and we are doing that.

Every day we hear from people all over the world. However, there are still more people to reach. There are still more people living with pemphigus/pemphigoid who are unaware of our existence, feeling alone. We are working to reach as many people as we can so that no one has to feel alone, afraid or uninformed. With your help this year, we will continue on our path to assist all who need our help. We have much more work to do. We see a future without these diseases and we hope that we have helped all of you cope and find a way to live a full life in spite of them.

On another note, I would like to acknowledge all the wonderful people who have passed from our world this year. Their friends and families have acknowledged the Foundation with donations in their names. We send along to all those families our deepest sympathies.

This is probably the hardest part of my job. Fourteen people have died this year (not all from pemphigus or side effects, but all friends). It’s always hard to choose the right words because each loss affects us so profoundly. The thing that helps me deal with loss is thinking how lucky I was to have known these people. Each individual who comes into our lives enriches us in some way. I believe that this is the best way to celebrate someone we knew and loved.

One person close to us, Len Kassan, died recently. He and his wife, Marcia, made a big difference in the early days of the Los Angeles Support Group. Because of their efforts, this group is one of largest and most active ones. The Kassan family also played a big part in helping us with our annual fund-raising. Len had been living with pemphigus for a long time, taking prednisone almost the whole time. We will miss his kindness, his warmth and his compassion.

I must say that I am honored to have known him. For those who died in some way from pemphigus, we will work even harder to do whatever we can so that no one else has to die from this disease. The Foundation’s commitment and the commitment of all the doctors and researchers working toward a cure for pemphigus gives us all hope that we will beat this disease.

WE ARE COMMITTED!

The National Pemphigus Foundation

"A common hope, an uncommon bond"

The National Pemphigus Foundation is a nonprofit organization. Our goals are to increase awareness of pemphigus or pemphigoid among the public and the medical community, to provide information and emotional support to people living with pemphigus or pemphigoid, their friends and families; to provide referrals to specialists; and to support research into advanced treatments and cures. Founded in 1994.

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Why blisters occur at different sites

By Grant J. Anhalt, M.D.
Johns Hopkins Dermatology
I will attempt to clarify what we know about the antibody response in various forms of pemphigus and how the distribution of the targeted antigens affects the location of lesions. The synthesis of this work has been proposed by Dr. John Stanley, with key published advances from Dr. Masa Amagai and Mai Mahoney, Ph.D., P. Koch and others. John Stanley refers to his concept as the "desmoglein compensation hypothesis". The key to this hypothesis is the desmogleins (pemphigus antigens) are key adhesion molecules that keep cells attached to each other. In some areas of the body, there are two desmogleins present, and both have to be damaged to cause cell detachment - in some areas only one desmoglein may be present at some level in the skin or mucous membrane, and there only one desmoglein has to be damaged to cause cell detachment. The following summary is a recent editorial from the Journal of the American Academy of Dermatology (1).

<table>
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<tr>
<th>Form of pemphigus</th>
<th>Antigens targeted by autoantibodies</th>
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<tbody>
<tr>
<td>Pemphigus foliaceus</td>
<td>Desmoglein 1</td>
</tr>
<tr>
<td>Pemphigus vulgaris (only oral lesions)</td>
<td>Desmoglein 3</td>
</tr>
<tr>
<td>Pemphigus vulgaris (oral and skin lesions)</td>
<td>Desmoglein 3 and Desmoglein 1</td>
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<tr>
<td>Paraneoplastic pemphigus</td>
<td>Desmoglein 3, Desmoglein 1 and Plakin proteins</td>
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The simplest situation is pemphigus foliaceus, where blistering occurs in the most superficial layer of the epidermis. These patients have antibodies that are directed against desmoglein 1. This desmoglein is expressed mostly in the upper levels of the epidermis, and antibodies binding to it cause cell detachment (blistering) only where it is primarily expressed. Desmoglein 1 is present in oral epithelium, but oral lesions "never" occur because there is co-expression of desmoglein 3 in the superficial oral epithelium, and the desmoglein 3 is able to keep the cells from detaching, even if desmoglein 1 is knocked out by the antibody (2). Also, in skin, desmoglein 3 is expressed in lower levels of the epidermis, so that knocking out desmoglein 1 doesn't cause blistering there, just in the upper levels of the skin where desmoglein 1 is the only key adhesion molecule present.

In pemphigus vulgaris, antibodies impair the adhesive function of desmoglein 3 and cause acantholysis in the oral cavity, where this molecule seems to be of primary importance in maintaining cell attachment. The hypothesis that desmoglein 3 has such unique contributions to adhesion primarily in oral epithelium was is supported by new data. Recently, a "knockout" mouse was produced, where desmoglein 3 was eliminated by genetic manipulation (3). These mice lacked desmoglein 3 expression in skin and mucous membranes, but acantholysis occurred only in the mouth, and in a limited fashion in areas of trauma such as the snout and paws. The skin was not affected.

As pemphigus vulgaris progresses, many, but not all patients will develop cutaneous disease. This seems to be caused by a "spread" of the autoantibody response, and development of antibodies against both desmoglein 3 and desmoglein 1. If both these desmogleins are inhibited by autoantibody, not just oral, but also cutaneous blistering occurs (4, 5). This may represent an example of what has been called "epitope spreading" (6). This is a phenomenon seen in autoimmunity, where early in the disease course, patients make antibodies against one protein, but as the disease evolves, they then make additional antibodies against molecules that are similar in structure, or even unlike each other in structure, but are physically closely associated in a tissue.

Patients with pemphigus foliaceus generally do not develop epitope spreading. If they did, they would start to make antibodies against desmoglein 3 (as well as 1) and would then have pemphigus vulgaris. This has been observed, but it is actually a very rare event. Also, one can not have both pemphigus vulgaris and foliaceus, because pemphigus foliaceus is defined by the absence of antibodies against desmoglein 3.

References
Osteoporosis is one third more likely in pemphigus patients taking Prednisone

Beginning with this issue, we will bring you news briefs taken from various news sources including the Internet. This time we concentrate on osteoporosis.

Testosterone and osteoporosis

Does testosterone help prevent bone loss in older men? That was a possible conclusion of a study of 108 healthy men over 65 years of age in a study by Dr. Peter J. Snyder of the University of Pennsylvania in Philadelphia and reported in The Journal of Clinical Endocrinology and Metabolism in June 1999.

“Snyder noted that the study was prompted by observation that the loss in bone density and muscle strength in men aging normally are similar to those that occur in men with hypogonadism - a condition in which levels of hormone production are abnormally low,” said the report.

The test subjects were treated with a scrotal testosterone patch or a placebo. Most of the subjects were calcium deficient and took calcium supplements as well. Those with the patch showed signs of increased bone mineral density.

The report said that “a comparison of bone density in men treated with testosterone and calcium with those treated with a placebo and calcium did not find a difference in increases in bone density. However, men with the lowest pretreatment levels of testosterone did have increased bone density.” The group also replaced about six pounds of fat with about four pounds of muscle with no increase in the risk of prostate cancer. More study will have to be done to confirm the hypothesis.

Women not told of HRT benefits

Osteoporosis is aggravated by menopause. Menopause speeds up the bone depletion that occurs during normal aging processes. Curvature of the spine, fractures of the vertebrae or hip, loss of height, and pain are some of the symptoms of osteoporosis. About 20% of women over age 50 have or are at risk for bone fragility and fractures, especially hip fractures, as their estrogen levels decline. This is especially important for pemphigus patients, because osteoporosis is 30% more likely for those taking prednisone than the general population, according to the recent international survey published by the NPF in November 1999.

Hormone replacement therapy (HRT) provides estrogen the body no longer makes. It relieves the symptoms of menopause, including an increased rate of bone loss. In a recent survey of over 1,000 women, 30% of past hormone replacement therapy (HRT) patients and over 50% of those not using HRT, said they received no information about the benefits of the therapy.

“These decisions are notably complex because women’s values, preferences, and risk levels differ and because the scientific evidence of benefits and risks continues to evolve,” said Dr. Andrea LaCroix from the Center for Health Studies in Seattle, Washington. The report was in the December 1999 issue of Women’s Health Issues. Gynecologists and women’s health care specialists were far less likely than family practice health care providers, of any age, men or women, to encourage HRT use.

Study of men’s osteoporosis funded

Seven medical research institutions will share $23.8 million to study osteoporosis in men. The grants come from the National Institute of Aging, the National Cancer Institute and the National Institute for Arthritis, Muscular Skeletal and Skin Diseases, (NIAMS).

While 80% of the 28 million Americans who suffer from osteoporosis are women, the study will follow 5700 men in a clinical trial for an average of 4.5 years.

Doctors hope to learn more about the causes and progression of the loss of bone mineral density. According to the recent NPF international survey, about one third of pemphigus patients suffer from osteoporosis.

“As other causes of early mortality in men are reduced, there is a need to focus on chronic disabling conditions like osteoporosis that will limit their independence,” said Joan McGowan, chief of the musculoskeletal diseases branch at NIAMS.

Grants will go to the University of California at San Francisco and San Diego; Stanford University; the University of Minnesota; the University of Alabama; Oregon Health Sciences University, and the University of Pittsburgh.

Exercise video for osteoporosis patients

The National Osteoporosis Foundation (NOF) announced the release of BeBoneWise—Exercise, the official NOF weight-bearing and strength-training exercise video by Lisa Hoffman, MA.

The program includes sections on warm-up, aerobic and whole body weight-bearing activities, wall, chair and floor exercises.

The tape comes with an exercise band and safe movement handbook which avoids movements that are unsafe for people with osteoporosis, such as twisting or jerking the spine or bending forward from the waist.

The package is $19.99 plus $5.00 shipping and handling. This video is not recommended for people who are frail, have had a fracture or fall frequently.

If you are interested, contact the NOF in Washington, D.C. at (202) 223-2226, visit them on the web at www.nof.org or use the link to the NOF on the NPF website.
NPF insurance survey

Most patients pleased with insurance companies

By Janet Segall
Executive Director

Fifty people responded to our insurance questionnaire. We would have liked more responses, especially from those who have had problems with insurance, but we can make an estimate from the returns we did get.

When they were first diagnosed, 96% of respondents had insurance. Seventy percent had private insurance and 14% had private insurance and Medicare. Most people, 56%, have continued with their initial coverage, 14% changing from private insurance alone to Medicare with private insurance. Two people did not have insurance when diagnosed, with only one not having insurance now. No one lost their insurance due to diagnosis of their disease.

Seven people applied for Social Security Disability. Five people or 10% pay for their own health care. Two people indicated that they had to go outside their insurance company to see a specialist and pay for it out of their own pocket.

Eighty percent of respondents said their doctors were familiar with current treatments. Those whose doctors weren't were able to either see a specialist or their doctors agreed to consult with one. Fourteen percent said they had to challenge their insurance company to see a specialist.

Eighty percent indicated that their health care provider covered drug costs. Fourteen percent said that they had partial payment, but since we didn't specifically ask that questions, we assume that number is probably higher.

Eighty-six percent had no trouble getting coverage for certain procedures but blood tests, bone scans and psychological pa-

70% Private insurance
14% Private + Medicare
12% Other
4% No insurance

tients had trouble getting approval. Final approval took an average of 2.5 months.

Half had no problems getting the required medications, but the drugs most people had trouble getting approval for were Imuran and CellCept. One person did not get the approval needed for CellCept.

We received one questionnaire from New Zealand. It seems the system there is similar to ours in many ways.

AARDA gives tips for chronic illness

AARDA (American Autoimmune Related Diseases Association) has a page on its website devoted to advise for those with a chronic illness.

Some tips include: understand your illness and the treatment plan established by your physician. In short, don't be intimidated by the medical profession. Fatigue may accompany many of the autoimmune diseases. If you have an autoimmune disease that requires a special diet, following this diet is very important.

You can expect to have a variety of emotional responses. Understanding these responses and their causes will help you determine what works best for you in overcoming them. Chronic illness has so many ups and downs that it can be emotionally draining. Understand that you did nothing to cause your illness and that life is not always fair.

For more information visit www.aarda.org/copling_art.html.

Are you ready to take control of your health?

AARDA gives tips for chronic illness

Information is the key to making the best choices. In turn, understanding your options relieves fear and inspires the confidence to take action against what troubles you. There is no doubt about it: knowledge is power. And we have the information you need. Sign up now.

Copy or cut out this form, print clearly and return with donation to: The National Pemphigus Foundation P.O. Box 9606, Berkeley, CA 94709-0606.

I would like to receive the quarterly newsletter. I enclose my suggested annual tax deductible donation of $50.00* ($65.00* outside the United States) to help offset the costs of the NPF website, the online support group and the newsletter, etc. Please make contributions in U.S. funds only.

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I would like to receive the newsletter but I am under a financial hardship. I enclose a donation of $________ to help cover the costs.

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THE JOY OF SOY

One of the latest media darlings is the soybean. The “overnight” success of this overachieving legume started in Northern China 5,000 years ago. Today, press releases about the beneficial effects of the isoflavones in soy on cancer, heart disease and osteoporosis bounce from one end of the media to the other. What a growing number of people have known for quite some time, the rest of the world is just awakening to: soybeans are amazingly good for the body.

As more and more people come to the realization that diet plays a vital role in health, soybeans and soy products, such as tofu, are turning up with increasing frequency on dinner tables around the globe.

A source of high quality vegetable protein, soybeans contain nine amino acids (building blocks of life). Soy is a good source of calcium and it is easy to digest. One important reason for the beans popularity is their versatility, both in form and what you can do with those forms.

THE VERSATILE SOY FAMILY

Whole beans - Come in two types: 1) whole soy beans, dry, picked when mature, tan or yellow in color, 2) Green soybeans, picked just before maturity, similar in size and color to peas. Use as side dish, snack, in soups and salads or mixed with other ingredients. Mature beans are higher in calories, fat and protein.

Milk - Plain, unfortified soymilk is a great source of protein, B-vitamins and iron. It comes unflavored or in a variety of flavors including chocolate, vanilla, and almond. There are also reduced fat varieties.

Flour - Contains no gluten, so it does not replace regular flour with more than 30% soy flour or dough will not rise. Adds nutty taste, may brown quicker. Also used to thicken gravy. Defatred soy flour is high in fiber.

Textured Soy Protein (TSP) - Dehydrated form which comes in powder or chunks for use as a meat replacement.

Protein isolate, a powder to add to shakes, baked goods and such.

Miso - A flavoring agent made with soybeans, rice or barley, salt and water. It is fermented up to three years to intensify flavor.

HONEY DIJON SAUCE

1 package (12 ounces) soft tofu
5 Tbs dijon mustard
4 Tbs honey

Mix all ingredients well. Keep refrigerated. Serve with chicken or veggie nuggets, pork beef, fish or poultry. Yield: 1 3/4 cups. Serving size: 2 Tbs. Per serving: 41 calories, 1 g fat, 0 g sat fat, 2 g protein, 6 g carbohydrate, 35 mg sodium, 0 mg cholesterol.

HEALTHY CHILI

2 cups firm tofu, crumbled
1 clove garlic, minced
1 tablespoon chili powder
2 tablespoons Worcestershire sauce
1 cup onion, chopped
1 large green pepper, chopped
1 carrot, thinly sliced
2 tablespoons soy sauce
1 cup tomatoes, chopped
1 can (16 ounces) tomato sauce
1 can (15 ounces) dark red kidney beans
1/2 teaspoon dried basil, crushed
1 teaspoon cumin
1 teaspoon cayenne pepper
1 can (6 ounces) tomato paste, optional
Salt to taste
4 cups cooked brown rice
Garnish: minced onion, grated cheddar

In a mixing bowl, combine tofu, garlic, chili powder and Worcestershire sauce; set aside.

In a large skillet, saute onion green pepper and carrot in soyoil until onion becomes transparent. Add tofu mixture cook and stir 3 minutes over medium heat. Add tomatoes, tomato sauce, kidney beans, basil, cumin, cayenne and, if desired, tomato paste. Cover and simmer for 30 minutes. Salt to taste. Serve on brown rice. Garnish with minced raw onion, grated cheddar cheese and avocado, as desired. Makes 8-1 cup servings.

Per serving: 320 calories, 17 grams protein, 43.8 grams carbohydrate, 10.5 grams fat, 0 cholesterol, 597 milligrams sodium.
**PASTA SAUCE**

2 tablespoons soybean oil
1 cup diced onion
1 cup diced zucchini
1 cup sliced red pepper
1 cup sliced mushrooms
1 jar (16 oz) spaghetti sauce
1/2 teaspoon each Italian seasonings and salt
1/8 teaspoon pepper
4 cups your favorite cooked pasta

Heat oil in large non-stick skillet over medium-high heat; stir in onion, zucchini, pepper and mushrooms. Sauté until vegetables are crisp-tender. Add spaghetti sauce and seasonings; mix well. Bring mixture to boil, reduce heat and simmer 5 minutes. Stir in pasta.

Makes 4 to 6 servings. Per serving: 413 calories, 10.3 grams protein, 13.4 grams fat (296 calories from fat), 64.9 grams carbohydrate, 0 mg cholesterol, 5.3 grams fiber, 841 mg sodium.

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**CHESAPEAKE SOY CAKES**

2 cups cooked and drained soybeans*
2 tablespoons chopped parsley
1 cup fresh whole wheat bread crumbs
1/2 teaspoon each thyme, crushed, and salt
1/2 cup finely chopped onion
1/4 teaspoon ground pepper
2 cloves garlic, minced
1 egg, beaten
1/4 cup grated carrots
Vegetable (soybean) oil
1/4 cup soy protein isolates
4 lemon wedges

Coarsely mash cooked soybeans until lumpy. Combine all ingredients in large bowl. Form 1/3-cup portions into patties. Cook in a lightly oiled, nonstick skillet over medium heat until thoroughly heated and browned on both sides. Serve with a lemon wedge.

*Add 1 pound dry soybeans to 6 to 8 cups boiling water; boil 5 minutes. Cover pot, remove from heat and let stand 1 hour. Drain; add 6 cups water. Do not add salt at this point or it will delay the softening of the beans. Bring beans and water to boil; reduce heat and simmer, with lid tilted on pot, about 3 hours or until beans are tender.

Makes 4 to 6 cups cooked beans. Per Serving: calories 240, cholesterol 42.6 mg, protein 19.2 grams, fiber 5.7 grams, fat 8.4 grams, sodium 189 mg, carbohydrate 24.4 grams, calories from fat 30%.

**SMOOTHIES...**

Using your favorite smoothie recipe, replace the milk or other liquid used with all or a portion of soy milk. Adding tofu or soy protein isolate (powder), to smoothies or milkshakes is another easy way to increase the amount of protein and vitamins.


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**The Anhalt Tape**

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

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

Suggested donation of only $150.00*

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The Secrets of Social Security

By Jennifer Romero,
Licensed Clinical Social Worker

If you are a person with pemphigus whose condition is severe enough to prevent you from doing any gainful work activity, you could be eligible for assistance from the Social Security Administration (SSA).

Pemphigus is described in the SSAU Publication No. 64-039 Disability Evaluation Under Social Security, Section 8.03 (page 58) listing of eligible impairments. The language the SSA uses is: "Pemphigus, erythema multiforme bullous, bullous pemphigoid, dermatitis herpetiformis. With extensive lesions not responding to prescribed treatment."

The decision to apply for assistance from the SSA is never an easy one. The process of applying for assistance is time-consuming and often frustrating. The definition of disability in the Social Security law is a strict one. To be eligible for benefits, a person must be unable to do any kind of substantial gainful work because of a physical or mental impairment (or a combination of impairments) which is "expected either to last at least 12 months or to end in death."

This is harsh language. However, it is best to utilize the same language the SSA uses in your own application where it is applicable. In other words, when you file your initial application (or are writing a letter of appeal) discuss your own case of pemphigus in the context of the above definition. For example, you could say something like: a diagnosis of pemphigus means I have an autoimmune blistering disorder, pemphigus is a lifetime disease for which there is no known cure.

If, because of a medical condition, a person cannot do the work that they performed in the past, then age, education, and past work experience are considered in determining whether the person can do other work. If the evidence shows that the person can do other work, the Social Security Administration will pay less than the amount paid for their work, they cannot be considered disabled for Social Security purposes.

Working through any government bureaucracy can be overwhelming and exhausting. Some of you may have previously applied for SSA assistance and been denied such assistance. You may have given up without appealing the decision because it was too much trouble. This article serves two purposes: 1) to explain how to facilitate your own application process, and 2) to encourage those of you who are eligible to seek assistance based on your rights as a disabled person. This article is about adults who have been diagnosed with and are undergoing treatment for pemphigus.

Adults (over 18 years of age) who are severely disabled may be eligible for monthly benefits under one or more of the programs the SSA administers. Both the SSI and the Social Security Disability (SSD) programs provide a monthly income for people with severe disabilities.

However, the eligibility requirements for the two programs are different. The SSI program provides monthly income to people who are age 65 or older, or are blind or disabled, and have limited income and financial resources. Effective January 1999, the SSI payment for an eligible individual is $500 per month and $751 per month for an eligible couple. If you are married, and only one person is eligible, a portion of your spouse’s income may be counted. In addition, your financial resources (savings and assets you own) cannot exceed $2,000 ($3,000 if married). You can be eligible for SSI even if you have never worked in employment covered under Social Security.

The Social Security program pays benefits to disabled or retired workers and their families and to the families of deceased workers. To be eligible for Social Security disability benefits, you must be disabled and must have earned a minimum number of credits from work covered under Social Security. (The required number of credits varies depending on your age at the time you became disabled.) SSD benefit amounts and eligibility criteria will depend on your work and income history at the time you are determined to be disabled.

Generally, to be eligible for SSI, an individual also must be a resident of the United States and must be a citizen or a noncitizen lawfully admitted for permanent residence. Also, some noncitizens granted a special status by the Immigration and Naturalization Service may be eligible.

Medicare is a Federal health insurance program for people age 65 or older, people of any age with permanent kidney failure, and certain people with disabilities (including those with pemphigus). The two parts of Medicare are hospital insurance (Part A) and medical insurance (Part B).

The hospital insurance program (Part A of Medicare) helps pay for inpatient hospital care and certain follow-up care. It is financed by Social Security taxes paid by employees, employers, and the self-employed. People age 65 and over are eligible, on a premium-free basis, if they are entitled to monthly Social Security or railroad retirement benefits.

People under age 65 are eligible for premium-free hospital insurance if they have been entitled for more than 24 months to disability benefits under the Social Security or railroad retirement systems. Disabled people under age 65 who have worked long enough in covered employment to be insured for Medicare purposes are also eligible.

The supplementary medical insurance program (Part B of Medicare) helps pay for doctors’ services and other medical expenses. It is a voluntary program that is financed through monthly premiums paid by the enrolled individuals and through Federal gen-
eral revenues. Most states also offer supplemental programs to those eligible for Medicare on an individual, premium-paid basis. Anyone who is entitled to Part A of Medicare on a premium-free basis can enroll for Part B. (Most of these people are automatically enrolled in Part B, unless they sign a statement that they do not want Part B coverage.) Also, people age 65 or older who are not entitled to Part A can generally enroll in Part B.

Under the law, people who receive SSI generally are covered under the state Medicaid program. Within broad federal requirements, each state decides its criteria for Medicaid eligibility and the amount of medical care and related services covered. States generally provide coverage for people who receive cash assistance, such as SSI payments. They may also provide coverage for people who are not eligible for cash assistance but who are unable to pay their own medical expenses.

Remember the most important benefit from SSI is the comprehensive medical insurance provided by Medicaid. Often, being eligible for Medicaid is enough for a family to continue to be financially solvent while also coping with a disabling disease. Further information about the state's Medicaid program may be obtained from the people in any public assistance office.

Children with pemphigus could also be eligible for Supplemental Security Income (SSI), however, their criteria for eligibility are different. To apply for SSI benefits for a child with pemphigus you may telephone 1-800-772-1213 or request an SSI application for a child at your local social security office.

To apply, the application process begins with a simple telephone call. The number to call is 1-800-772-1213. This phone call "starts the clock ticking" to measure the date from which past benefits will be paid. An SSA representative will ask you a few questions (this is also an opportunity for you to ask your questions) and schedule you for a telephone interview. A local SSA representative will then contact you at the scheduled time. You may also visit your local social security office to apply. You can locate the telephone number and address of your local social security office in the telephone book. If you decide to visit in person, it may be most convenient to telephone ahead and schedule an appointment with a claims representative.

Why appeal the denial of an SSI application? SSA turns down many applications for SSI and SSD benefits. However, when applicants appeal these decisions, many are able to reverse the denial. Then they may receive retroactive benefits, back to the date of the original application. Because people often express anxiety about writing a letter of appeal, I have included a sample letter as Appendix A to this article.

If an applicant is found ineligible, the SSA sends a "notice of denial," which explains whether the denial is based on financial or medical reasons. The applicant has 60 days from the date the letter is received to file an appeal. There are four stages in the appeals process. An applicant may be successful at any of these stages, but must follow each step in the designated order: (1) Reconsideration, (2) Administrative Law Judge hearing, (3) Social Security Appeals Council review, and (4) Civil lawsuit in the U.S. District Court. An applicant has 60 days to complete each step.

Legal assistance is not required for an appeal, however, it can be extremely helpful, especially after reconsideration. Your local legal aid or legal services office can help if you cannot afford an attorney; their lawyers and paralegals handle many such hearings. Remember, most applicants are able to manage their first appeal without legal assistance.

Working up a case. The SSA defines a disability for adults as "the inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." A medically determinable impairment is based on medical evidence consisting of signs, symptoms, and laboratory findings. People with diagnosed pemphigus have had multiple laboratory tests in the process of their being diagnosed, however indirect immune florescence (from biopsy) is the standard laboratory test used to confirm the diagnosis of pemphigus.

While applying, it is important to keep copies of all correspondence and records of all telephone calls with your SSA representative. You must be diligent about deadlines. If you are late for a deadline, you will need to start the whole process again from the beginning. You can designate a representative to assist you in your correspondence with the SSA. A representative will receive copies of the correspondence the SSA sends to you. This can be especially helpful if you are too ill to keep up with your own correspondence.

View your disability from a broad perspective. Say you have a diagnosis of pemphigus vulgaris, also be aware of any additional diagnoses you may have received secondary to the treatment of pemphigus (for example, osteoporosis, diabetes, cataracts, immune suppressed status, and pain).

Adults are only evaluated based on medical factors and evidence. The SSA will evaluate your pain based on:

1. Your daily activities;
2. Duration, frequency, and intensity of pain;
3. Precipitating and aggravating factors;
4. Dosage, effectiveness and side effects of medication; and
5. Functional restrictions.

Provide information to the SSA that is as complete and detailed as possible. Be prepared to provide names, addresses, and telephone numbers of your physicians. Be ready to provide dates of hospitalization and your medical record number. Be able to discuss the details of all medications you have taken and are currently taking (including any life adjustments).

Build a relationship with your disability analyst. Find out the name and telephone number of the analyst assigned to your case. Find out if any particular information is needed by the analyst and facilitate their access to this information to the best of your ability. Decide which disabilities describe your Continued on page 10
RE: Appeal for SSI Disability Benefits for YOUR FULL NAME (SS# XXX-XX-XXXX)

Dear Mr. Doe:

On DATE your office sent a letter informing me that my application for Social Security Disability benefits was denied. I wish to appeal this decision.

Your reasons for denying benefits were: (1) that my condition is not expected to remain severe enough for 12 consecutive months to keep me from working, and (2) that my age/education suggest my ability to perform substantial work.

My reasons for appealing your decision are: (1) according to Disability Evaluation Under Social Security p. 58 Section 8.3 Pemphigus with extensive lesions not responding to treatment is a listed eligible condition, and (2) Pemphigus vulgaris (PV) (the most involved form of pemphigus) is not a skin disorder, it is rather and most significantly an autoimmune disorder which once diagnosed is a lifetime disability.

Standards of care for patients with PV in its severe form involve a combination of systemic glucocorticosteroids, immunosuppressive drugs, and plasmapheresis. Patients with severe PV require medical specialists in both immunology and dermatology to monitor their care. Given that I am still not in a state of remission from my disease (initially diagnosed DATE) and that I am undergoing immunosuppressive therapy, I must request an appeal of your decision.

PV symptoms can sometime be controllable with steroid treatment alone; however, in my case this is not the case. My dependence on autoimmunity suppressors places me in a more precarious position relative to work.

Whereas my education and age suggest my ability to do substantial work (and indeed I would prefer to be able to work) I would encourage you to consider my case from the perspective of a person with a suppressed immune system. I must be extremely cautious with regard to exposure to people in general. People with colds, viruses, etc. represent extreme, potentially life-threatening risk for me.

Should plasmapheresis become the next step of my care, my treatment would be more akin to a person receiving renal dialysis and my case should be examined accordingly. Plasmapheresis is considered a steroid sparing treatment. Logically, since the problem is in my blood (my skin lesions are only symptoms of an underlying autoimmune disorder) the preferred course of treatment would be to clean my blood of the antigens causing antibody reactions. As I am sure you are aware, the side-effects for long-term use of corticosteroids are often debilitating in and of themselves. Although I am still in the process of advocating both for plasma-sparing treatments and for the consultation of an immunologist within my health care plan, I have not yet been successful in obtaining these resources.

In fact, I have been rehospitalized twice since I last examined my case. Both of these hospital admissions involved adverse reactions to the steroid treatments. I now have prednisone-induced diabetes. Also, I have extremely limited ability to move (even between the bed and the bathroom) because of severe muscle spasms in my back. I am, at present, receiving physical therapy with the hope of rehabilitating my capacity for independent movement. Long-term use of steroids is associated with joint pain and osteoporosis. On DATE I was diagnosed with osteoporosis by CAT scan.

I consider it my right and my duty to pursue Social Security Disability benefits because my disease is a very rare (incidence 0.5-3.2 cases per 100,000 per year) lifelong disorder and one which is not well understood.

It is the function of your agency to provide the safety net necessary for persons such as myself, suffering with PV, so that we may obtain lifesaving medical treatment until a cure can be found.

Please consider my case carefully. Whereas it is true that my disease has only been diagnosed since DATE, it is probable that I have struggled with PV (undiagnosed) for significantly longer. Furthermore, since my case is severe (i.e., requiring hospitalization, high-doses of steroids, immune suppressors) and not yet in remission I respectfully submit this appeal.

Sincerely,

Your full name
SS# XXX-XX-XXXX

cc: Your dermatologist, your doctor at their location, your interest, full name of SSI Claims Representative

...social security

Continued from page nine

situation and which can be documented under SSA regulations. Draft a persuasive letter to the analyst which ties your position to the factual evidence (see sample on this page). Such a letter could be submitted at the time of your initial application, it is not mandatory, but it could establish a basis for your request for assistance for a very rare and little understood disease. Send a copy of this letter to the SSA analyst as well as to your treating physicians.

Talk with your treating physicians about your intention to apply for social security benefits. Often physicians are only too willing to help but they are unsure of the language they need to use when discussing your medical status with the SSA. Sharing the letter you plan to send to your SSA representative with your physicians will enable them to use similar concepts and terms in their own letters.

This decision to apply for social security benefits is often reached after a serious and prolonged illness. No one chooses to be disabled. However, recognizing that one is disabled is a personal responsibility to pursue resources and financial support which can promote access to appropriate self care and health care. A diagnosis of pemphigus requires many, many life adjustments. Your medical status may improve significantly with time. When your situation is improved your disability may need to be reevaluated. Some people with pemphigus improve significantly with time and treatment and do eventually return to work and relinquish their social security benefits.

Although applying for SSI or SSD can be a stressful process it is important to keep focused on the long-term goal of minimizing stress in your life. Worry about income and health care insurance are sure to cause stress. If you believe you qualify to receive assistance from the SSA, it is worth the hassle of applying and appealing. When you are finally successful, you will be able to enjoy a prolonged period of time free of worry about access to quality health care.
...Sciubba joins NPF Board

Continued from page one

Oral Pathology from 1974-1975 at the American Dental Association and attained Diplomate status from the American Board of Oral Pathology in 1976.

He was appointed as Chairman of the Department of Dental Medicine at the Long Island Jewish Medical Center in July of 1983, serving in until November 1999. He became Professor of Oral Biology and Pathology in 1984 at the School of Dental Medicine, State University of New York at Stony Brook and served as President of the Medical Board from 1995 to 1998.

Dr. Sciubba has authored or co-authored several books and monographs dealing with oral and maxillofacial pathology and salivary gland pathology and has published over 500 scientific papers, chapters and abstracts. He was elected as a Fellow of the American College of Dentists, the International College Dentists, the New York Academy of Sciences and the American Association of Hospital Dentists and is a Diplomate of the American Board of Oral and Maxillofacial Pathology.

He holds numerous academic awards, honors and distinctions, is a consultant to the National Institutes of Health (NIH) and served as Chairman of a National Consensus Development Conference on Oral Complications of Cancer Therapies at NIH. He currently serves on the editorial boards of several journals and is an associate editor of the Journal of Oral Pathology and Medicine.

His wife Dolores and he are the parents of Dana Leonard and Jimmy Sciubba and reside in Pasadena, Maryland.

New Therapy for Ocular Cicatricial Pemphigoid (OCP)

Ed Tenner, ophthalmologist and pemphigus patient, brought to our attention an article the November 1999 issue of Ophthalmology titled "Interventional Immunoglobulin Therapy for Ocular Cicatricial Pemphigoid (OCP)" by C. Stephen Foster & A. Razzaque Ahmed. It provides a summary of how treatment for OCP developed. The fact that topical medications i.e. drops are not effective and that immunomodulating agents were found to work is noted.

Because of side effects of oral steroids (Prednisone) alone, agents like dapsone, methotrexate, azathioprine, & cyclophosphamide were added & found to control most patients. This study was to try & control the disease in the 10% who didn't respond to the usual treatment. Ten patients, between the age of 52 to 77 were treated for 16 to 23 months with no side effects and all patients showing some improvement with intravenous immunoglobulin.

It worked for me

Dan Goodwill, NPF Support Group Leader in Toronto, found a treatment which helps solve a problem with long lasting lip blisters. It is Prograf (Tacrolimus) 0.1% in Acéphor cream. It is a derivative of a soil fungus as is cyclosporin. It has similar immunosuppressive properties, but is 1 to 1000 times stronger.

"I have tried Kenalog in Orabase and Ultravate for years without success," reports Goodwill.

To apply it to your gums successfully, you must use a plastic gum plate prepared by your dentist. Take a tissue, dry your gums with tissue in the affected areas, apply the Prograf twice a day, leave the gum plate in place, and watch your gums improve.

Heart S2 Heart

If you need to talk to someone about pemphigus, contact one of four volunteers.

<table>
<thead>
<tr>
<th>State</th>
<th>Name</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
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Goodwill leads Toronto to develop a booklet

By Dan Goodwill

The Toronto support group held its fall meeting on November 7. There were several new members in attendance. Everyone in attendance received the new Pemphigus Vulgaris Patient Information, a booklet coauthored by Dr. Daniel Sauder, Mark Unger and Dan Goodwill.

A number of interesting issues surfaced at the meeting. First, it was agreed that it is important that the illness not be left untreated. One of the new members advised that her doctor told her that "I cannot feel your pain. When you are in pain, come back and I will treat you". This individual was getting increasingly more lesions, but was not in dire pain.

The group agreed that the patient should obtain a referral to another doctor who will prescribe a steroid drug and begin the process of bringing the disease under control. Waiting until you feel pain is not a recommended approach with this illness.

There was also a discussion of how to increase time with your dermatologist at a Teaching Hospital. It was agreed that the patient should come prepared with a status report on his or her illness when she is met by the resident, rather than wait for the resident to peruse the file and ask a set of basic questions. The patient should come equipped with a set of questions. This will allow the patient to more quickly gain an audience with the experienced dermatologist, while minimizing the time spent with the less knowledgeable resident. It was also suggested that the patient be aggressive and insist that all of their questions be answered before they leave.

The role of the support person or caregiver was discussed. Some of the caregivers expressed the view that communicating with individuals on high doses of prednisone requires a certain skill. When the PV patient shows drug induced behavior such as moodiness or a temper tantrum, it is important for the caregiver to signal to the patient that they are not acting on their normal self. This gives the PV patient a sign that they need to find a way to regain their composure.

The early tapering of prednisone was also discussed. One patient, who was on a high dose of prednisone for an extended period, and suffered a number of bone fractures, expressed the view that you need to begin the tapering regimen as soon as you begin to bring the disease under control. Staying on 60 or 80 mg a day of prednisone, for an extended period, can have quick and unfortunate consequences. This patient advocated the immediate use of Fosamax, once you are on high doses of prednisone, to reduce the possibility of bone deterioration.

The next meeting is February 23.

---

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by Zukerman & Ingelfinger

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Peptimmune updates NY group, more blood drawn for research

By Joan DeLucie

Twenty-six members of the New York group met on Thursday, November 11, 1999 at New York University Medical Center. Dr. James Rasmussen, Vice President of Research and Development and Chief Scientific Officer for Peptimmune, gave a brief update on Peptimmune's research protocol and answered questions from members.

Dr. Rasmussen explained that Peptimmune's primary goal is to develop a therapeutic vaccine for Pemphigus Vulgaris and that the company is totally dedicated to making this work. He went on to say that there are no guarantees but that he does feel there is a good chance it will work.

Thank you to members of the New York group who volunteered to donate blood for Peptimmune’s research project and to Dr. Joyce Rico for making all the appropriate arrangements.

We discussed the annual fund-raising campaign and a special events committee was organized. The committee will meet to establish a telephone chain and contact each member to discuss their personal pledge and pledges from their family and friends. We also discussed our plans for a May golf outing.

During our Round Robin session, we welcomed two new members, Eva Gold and Janice Taylor, who gave narratives of their challenge with Pemphigus.

Our next meeting will be Thursday, February 24, 2000, 5:30 PM at New York University Medical Center. Check you mailbox for the announcement and please RSVP via email or telephone. See you then.

Segall addresses LA support meeting

By Carol Goren

The Los Angeles chapter met on October 17, 1999. Executive Director Janet Segall was in attendance and discussed the latest research. It was encouraging to hear that the research on developing a vaccine was going strong. Genzyme wants a vaccine developed 18 months from summer of 1999.

Before the vaccine could be offered to the general public however, there would have to be clinical trials. Members may be able to participate, providing they meet the criteria.

Janet discussed the National Pemphigus Foundation’s conference and stated that some of the best doctors in the country participated.

Janet also stated that they were planning a one day seminar in San Francisco. Doctors and specialists would participate. The conference is now scheduled for September 23, 2000.

The next meeting of the L.A. chapter is Sunday, February 6, 1:00-4:00 PM. at Encino Hospital, 16237 Ventura Blvd, Classroom, 1st Floor. We are honored to have Dr. David Woodley, dermatologist from USC as our guest speaker. We will have a sharing period before our guest arrives.

Annual events on tap for early 2000

Janet Segall, Executive Director of the National Pemphigus Foundation will attend the annual “NIAMS Day” in Washington D.C. on March 1, 2000.

NIAMS is the division of the NIH that deals with skin diseases. During these two days, the CPR-SDR (Coalition for Patient Advocacy for Skin Disease Research) of which the NPF is a member, will meet with the Director of NIAMS, Dr. Steve Katz, to discuss NIAMS funding and skin disease research.

That evening the Coalition meets with the SID (Society of Investigative Dermatology) members involved with “NIAMS Day” for dinner and to discuss the events for the next day. The following day they go to the "Hill" to educate Congressional members and their staff about the importance of increasing the NIH budget to help keep the nation healthy.

Also in March, the American Academy of Dermatology (AAD) will hold its major Convention in San Francisco. Dermatologists and students from all over the world come to take part in lectures and classes.

For later on in the year, the NPF is beginning to plan for a one-day conference to be held in San Francisco on September 23, 2000.
We begin the new century empowered by your generosity.

The best thing to give to your enemy is forgiveness; to an opponent, tolerance; to a friend, your heart; to your child, a good example; to a father, deference; to your mother, conduct that will make her proud of you; to yourself, respect; to all men, charity.

- Francis Maltland Balfour

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Thank you, one and all.
How we react to stress can be key to our health

By Hannah Lisa Reade

Hundreds of chemical changes occur in our bodies under stress that can cause illness, or worsen an illness that one already has, but what actually is stress? It is a physical and emotional reaction to the events in our lives. How we react can be key to our health and, with practice, under our control.

As you may have noticed, what is stressful for one person is not particularly stressful to another. My former job as a real estate agent was stressful to me, as well as having enjoyable aspects...but was not particularly stressful to my coworker. I had a different personality than she, was going through other stresses in my life, and reacted to the same job in a totally opposite way.

People react to stress in many ways: nail biting, hair pulling, overeating, undereating, too much or too little sleep, talking too loud or too fast, drinking too much alcohol, irritability, forgetfulness, confusion, inability to make decisions, rocking back and forth and muscle tension.

Some early physical signs could be eyelid twitching, headaches, back pain, stomachaches and other digestive problems, palpitations, and high blood pressure.

It is most important to learn what stresses you, and if you can’t get rid of the stress, how to choose healthy habits to release it and perhaps new ways to look at the situation. Here are some ways to manage your stress:

- Regular exercise is the number one coping mechanism offered by the experts. Be sure to check with your doctor first.
- Relaxation such as meditation, yoga, massage, warm baths, listening to your favorite music
- Enough sleep. Experts say this country is very sleep deprived...rest is needed for body repair as well.
- Healthy diet. Low saturated (solid at room temperature) fat, low salt, low sugar, lots of water, high protein for (those under the catabolic effects of prednisone). Eating a variety of unrefined (high fiber) fresh foods in moderate quantities is one concept agreed upon by most nutrition experts. Cut back on nerve jangling caffeine in coffee, tea, chocolate, and soda.
- Good relationships. Studies have shown close relationships lower health risks and that pets are good sources of unconditional love.

Other suggestions:
1. Visualization. Take a break and imagine being in a soothing place.
2. Don’t rehash a bad day. Let it go.
3. Listen to body pain. It may be a sign of stress.
4. Spirituality. Connect to something bigger than yourself.
5. Work for a cause or event. It gets your mind off your own problems and you help others which feels good.
6. Read or get the tapes or CDs of titles such as “Don’t Sweat the Small Stuff.” Now you know, so go do it!