NPF supports NIAMS Day

Immediately following her trip to the American Academy of Dermatologists convention in Orlando, Florida (story this page), NPF President Janet Segall participated, with the Coalition for Patient Advocacy for Skin Disease Research (CPA SPR) in NIAMS Day in Washington D.C. on March 11, 1998. NIAMS (The National Institute for Arthritis, Musculoskeletal and Skin Diseases) is the branch of the National Institutes of Health (NIH) which funds skin disease research. NIAMS goal is a 15% increase in the NIH budget for the coming year, and doubling the budget in the next five years. President Clinton has asked for an increase of approximately eight percent.

Dr. Stephen Katz, NIAMS Director, announced several new programs of research which NIAMS supports, including clinical research and compensation to Medical Health Centers for training and research purposes. Following the briefing the participants broke into groups and proceeded to Capitol Hill.

Joining Segall was Dr. Grant Anhalt, of Johns Hopkins Medical Center and Vice President in charge of Scientific Affairs for the NPF, representing the Society for Investigative Dermatology; Erica Byrne of Baltimore, Maryland, and others. The group met with Jenny Koppleson, Maryland Senator Paul Sarbanes’ aid on health issues. Segall and Byrne then visited with representatives of California Senator Diane Feinstein and Congressman Ben Cardin from Byrne’s home district in Maryland.

The following day American Autoimmune Rare Disease Association (AARDA) held a meeting to initiate cooperation between the various foundations and organizations related to autoimmune diseases.

Continued on page 11
President’s Message

Pieces of the big picture

A few things have come to my attention in the last few months that I would like to address. My trips to Orlando and Washington were a great success. I talked with intelligent, committed, interesting people dedicated to seeing diseases like pemphigus eradicated in our lifetime. I learned of the enormous costs autoimmune diseases put on our health care system.

When I first started the Foundation, my goal was to bring information and support to those individuals with pemphigus, their family and friends, and to increase public awareness.

I still consider this our first and main objective. But, from hearing the many stories of people going misdiagnosed, sometimes for years, the roller coaster of treatment that goes along with pemphigus, and the seemingly growing number of young adults being diagnosed, I thought how nice it would be to see this disease gone. I felt that we should add this goal to our agenda as well, by supporting research.

One of the most important ways to support research is gaining recognition from the public. We need to overcome the belief that pemphigus is, in and of itself, so rare that we are not important. This perception of our disease, I believe, shows little chance of changing unless we change our perspective and join the bigger campaign against autoimmune diseases.

Because of our involvement with pemphigus it is difficult to think of ourselves relative to other autoimmune illnesses, but in fact, there are some of us suffering not just from pemphigus, but from other autoimmune diseases as well (arthritis, myesthenia gravis, etc.).

The interesting point here is that, unlike many other autoimmune diseases pemphigus is one that is easy to identify. It can be diagnosed with a biopsy or even just a blood test. Skin cells can be grown in the laboratory, and researchers can see how the cells fall apart when attacked by the antibody. Because of the link between autoimmune diseases, pemphigus research may have far reaching implications in finding better treatments for all autoimmune diseases.

Pemphigus is not the only autoimmune disease from which my family suffers. Although it is my main aliment and focus (aside from arthritis which is creeping up on me) I have five relatives with autoimmune related diseases.

If research on pemphigus can help them as well, I will fight even harder to bring pemphigus to the forefront.

So, my point is, we should begin looking at pemphigus in a different way. We should look at it as part of the whole picture, and incorporate that image into our public awareness efforts. If research on our disease can have a major impact on all autoimmune diseases, this should be our emphasis in our goal to bring pemphigus into the public forum and raise funds for research as well as for the Foundation.

I would also like to address our need to be cohesive in our approach to contacting individuals who might be able to help us. Of course, anyone has the right to write letters and contact anyone they think might be able to help, but please make sure you indicate that you are writing for yourself and not as a representative of the Foundation, unless we have discussed it as something with which the Foundation agrees.

I feel very strongly about this. This Foundation has been working extremely hard to make the important contacts we believe we need. Unsolicited letters, however well intentioned, may overlap or jeopardize our efforts by appearing to come from the Foundation when they do not. This makes us seem disjointed and dis-connected, and that is the last thing we need if we want the recognition we want and deserve.

We have a lot of bright, talented and committed people in our group and on our side. Let’s work as a unit, together. I believe that this is the best for the benefit of us all.

Janet Segall
President

Correction:
The front page article entitled “Subject sought for Dapsone study” was edited not written by Dr. Victoria Werth.

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Cellcept: a promising new immunosuppressive drug

By Grant J. Anhalt, M.D. and Hossein Nousari, M.D.
Johns Hopkins University, School of Medicine

In February 1997, the FDA approved a new drug, mycophenolate mofetil (MFM, also known as Cellcept) with an approved indication for use in immunosuppression of patients that have received renal transplants, to prevent graft rejection. MFM is actually a new variant of a drug that has been studied for about 20 years. The active metabolite, Mycophenolic acid (MPA) had been used in the past for the treatment of severe recalcitrant psoriasis.

Although MPA was shown to be a useful drug, it was withdrawn due to a high incidence of side effects, primarily infections such as herpes zoster ("shingles") and gastrointestinal side effects such as nausea and stomach discomfort. MFM is the reformulated product that does not have these same drawbacks, and has better bioavailability than MPA.

This drug is commonly used in combination with cyclosporin and corticosteroids to prevent renal graft rejection. However, the role of MFM in immunologic-mediated skin diseases such as pemphigus and bullous pemphigoid seems to be promising. For example, its therapeutic profile and toxicities make it an attractive substitute for azathioprine (Imuran) in several circumstances.

For example, it could be useful in those patients who can not tolerate azathioprine due to nausea or hepatotoxic reactions, or in those patients who are at risk for azathioprine-induced toxicities due to deficiency of the enzyme thiopurine methyl transferase. The drug may have some advantages over azathioprine, in that it may be less mutagenic than azathioprine. That means that it may confer a lower risk of malignancies such as leukemia or lymphoma arising as a result of its use. This advantage is not proven, however, and it may be a very long time before this possible advantage can be substantiated. It is also not clear as yet whether it is actually as effective in practice as is azathioprine.

There are some early encouraging reports of its usefulness, referenced at the end of this article. Reports from Germany show that it is effective, when used in combination with Prednisone, in pemphigus vulgaris.

Our own experience has shown that some patients who can not tolerate azathioprine (usually due to nausea or abnormal liver enzymes) will tolerate MFM. Several patients have shown a good response to the drug, but in a couple of others it is not yet clear how effective it will be in suppressing activity of the pemphigus. We have not observed any serious side effects from the drug as yet. MFM is always used in combination with Prednisone. There is some early experience that it can be used without Prednisone to control some cases of bullous pemphigoid, but pemphigoid is quite different from pemphigus. There is no reasonable expectation that MFM could be used as monotherapy (without concurrent use of Prednisone) in pemphigus vulgaris. It is however, important to recognize that MFM is an additional agent that now can be considered for use in control of pemphigus vulgaris. For those who are interested in more details, some technical data and references follow.

MFM is an ethyl ester of mycophenolic acid which is metabolized to the active drug mycophenolic acid (MPA). MPA is a product of several Penicillium species. This immunomodulatory drug selectively inhibits inosine monophosphate dehydrogenase (IMPDH) in the de novo pathway of purine synthesis. This enzyme converts inosine monophosphate to xanthine monophosphate, an intermediate metabolite in the synthesis of guanosine triphosphate. This drug is more active in its inhibition of the type II isomer of IMPDH, which is found mostly in lymphocytes, and thus inhibits purine synthesis with potent cytostatic effects on both T and B lymphocytes. Lymphocytes are quite susceptible to this drug effect, for they minimally utilize the hypoxanthine-guanine phosphoribosyl transferase salvage pathway for purine synthesis.

Through these actions, MFM inhibits lymphocyte proliferation and antibody formation. This drug also inhibits leukocyte recruitment and glycosylation of lymphocyte glycoproteins involved in adhesion to endothelial cells. The drug is rapidly absorbed after oral administration, and antacids and cholestyramine may decrease its absorption. Around 5% of the drug is bound to albumin. It is nearly completely metabolized by glucuronyl transferase and over 90% of the drug is eliminated by the kidneys. The MFM glucuronide metabolite, which is increased in renal failure, increases MFM clearance by competing for its binding sites on albumin. MFM pharmacokinetics seems not to be affected by the concomitant administration of CsA.

The usual dose is one gm. every 12 hours. Potential side effects include nausea, stomach upset, vomiting, and diarrhea. There is no increase in nephrotoxicity, hepatotoxicity, hypertension, or neurotoxicity when MFM is used in conjunction with CsA and corticosteroids. Severe leukopenia (decrease in white cell count) has been reported in less than 3% of MFM-treated patients.

An increased incidence of lymphoproliferative diseases

Continued on page 13
NPF Support

Los Angeles

by Carol Goren

L.A. support group met on February
1. Lee Heins, Fund-raising Chairperson,
reported a very successful campaign. The
L.A. group raised approximately $9,500,
with donations still coming in. The money
will be targeted for research and adminis-
trative costs. Speaker, Dr. Jin Kim, UCLA
periodontist, addressed the group on
"Pemphigus: How it Affects your Mouth."
Janet Segall, NPF President and Joan
DeLucie, Chairperson of the New York
Chapter, attended the meeting. The next
meeting will be held on May 17 between
1:00 and 4:00 PM. If you are interested
in attending, please call.

Contact: Marcia Kassan
The NPF Southern California Chapter
Phone: 818-340-7180
Email: enterprise@loop.com

San Francisco

by Janet Segall

On January 17, the S.F. Support
Group met at University of California at
Davis with Dr. Sergei Grando, Professor
and researcher for the Department of Der-
matology. The meeting was held in Dr.
Grando's office with about 22 people at-
tending.

Dr. Grando and his team of research-
ers showed us slides on how pemphigus
attacks the skin and discussed their recent
breakthroughs in pemphigus research.
One of Dr. Grando's team, Vu Thuong
Nguyen, will present the results of their
research at the World Dermatological
Meeting this year in Cologne, Germany.

Dr. Grando then offered to do immu-
nofluorescent titer tests, on not only the
people with pemphigus, but their relatives
who were at the meeting as well.

We all volunteered. Dr. Grando sent
us the results of our titer test and offered
to send our attending physicians the re-
sults if requested.

We have not set a date for our next
meeting.

Contact: Janet Segall, President
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Fax: 510-527-8497
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Midwest

by Arlene Strauss

I attended the Foundation's first
American Academy of Dermatology con-
vention in Orlando, Florida, with Janet Segall.
We met many doctors from all over
the U.S. and other countries, and I was
pleased with the interest the physicians
expressed in the Foundation and its work.

This was terrific exposure for the
Foundation and hopefully the expressed
interest from the physicians will develop
into something very positive. So as not to
be repetitious, see the article on page one
in this newsletter.

There are plenty of Foundation t-
shirts, bumper stickers and buttons avail-
able for anyone who would like to join
our efforts in the Foundation's "Awareness
Program."

This is one of the best ways to cre-
ate public awareness of the disease and
the Foundation.

We would welcome everyone's help
in our very special cause. On page seven
of this newsletter there is an order form
for the above items. Please take a mo-
moment and order one or all of the items
listed. If possible, ask your friends and
family to help in our program to gain
awareness. Thank you.
A special "Thank You" to all of those
who contributed to our "1997 Holiday
Fund raiser," and to those who donated
their time and efforts to our important
cause. Contributions totalled $1,040.

Contact: Arlene Strauss
The NPF Midwest Chapter
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Lincolnshire, IL 60069
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Fax: 847-940-1256
Email: ChicagoPV@aol.com

Philadelphia

by staff reporter

Peace Love and Healing by Bernie
Segal was the focus of our last meeting.
Jim Marple led a spirited discussion. This
book discusses the mind-body connection
and we examined the ideas in the book
and the methods suggested.

Next meeting we will be talking
about the new book Coping with Pred-
nisone by Zukerman and Ingelfinger. A
Groups

date for the meeting has yet to be determined.

Contact: Barbara Sipe
Phone: 215-662-6440

New York

by Hannah Lisa Reade

On January 22 we were very pleased to have as our speaker Joseph G. Hayes Jr. M.A., P.T., a professor at Touro College and physical therapist. The topic was “Exercise during long-term steroid use.”

He started with discussing glucocorticoids and the five major side-effects, those being fractures, osteoporosis, aseptic necrosis of femoral and humeral heads, weakness and muscle mass loss.

Next he talked about bone development, steroids, general concepts and the role of exercise in preventing and treating osteoporosis.

One interesting point was that much of the bone loss occurs in the first 6 months on Prednisone. Also, if the stomach muscles are strong but the back muscles are not, it can cause you to lean forward.

Dr. Hayes emphasized how quickly one can lose muscle strength and bone if one is sedentary, and explained that the way to counteract that is with weight-bearing exercises that stress the bone and cause it to become more dense.

The weight should be increased to get the same effect when the bones become used to the weight your are lifting and are not stressed enough to build bone anymore.

This should be done gradually, not to the point of pain, and preferably under the guidance of a physical therapist, at least in the beginning to guide you properly to avoid incurring injury. He said if soreness lasted more than 2 days, you had overdone it.

We also received very informative handouts that illustrated the suggested exercises. These included the treadmill, stationary bike and stepper, as well as exercises without machines.

We then collected our dues and welcomed new members. Our next meeting will be Thursday, May 14 at 5:30 PM.

Contact: Joan Delucie
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Dix Hills, New York 11746
Phone: 516-586-6910
Email: jdelucie@aol.com

Toronto

by Dan Goodwill

The Toronto support group held its second meeting on March 22. The group is now meeting every sixth weeks at the North Toronto Memorial Community Centre at 200 Eglinton Avenue West. A core group of very caring and supportive people has come together.

As a start-up venture, the current mission of the group is to find other pemphigus patients located in Southwestern Ontario. Working in conjunction with several leading Dermatologists, a mailing is planned to Ontario based Dermatologists to inform them of the existence of the group.

The next meeting is scheduled for May 3 at 2 PM. At that time a former pemphigus patient, whose disease has been in remission for many years, will share his experiences with the group.

Contact Dan Goodwill
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Toronto, Ontario, M5N 1N7 Canada
Phone: 416-488-0453
Email: dgoodwill@clarkeunac.com

The NPF Website

The NPF Website is now located at www.pemphigus.org. Please update your bookmarks and let us know what you think and 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-DERM
www.aad.org

National Organization of Rare Diseases
P.O. Box 8923
Fairfield, CT 06892-8923
Phone: 800-999-6673
www.pcnet.com/~orphan

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

For medical information online:
www.rxlist.com (Drug information)
www.healthfinder.gov (Gen. health/links)
www.chronicill.net (Chronic illnesses)
Please use caution when evaluating medical information from the Internet.

Online support

Not part of the National Pemphigus Foundation, but open to anyone with email, the Pemphigus bulletin board is available by contacting: majordomo@lists.cyberwarc.com.

In the body of the message write: subscribe pemphigus_support. No other comments will be read by the computer. If you have any questions contact the Foundation.
The National Pemphigus Foundation Donor List

For all you have done, thank you.

The National Pemphigus Foundation would like to thank all those who contributed to our fund-raising drive, from January 1997 to March 1998; including those who gave less than $50.00 and were simply too numerous to mention.

Thank you to Len & Marcia Kassan for donating printing to the LA group and the Foundation. Special thanks go to Robert Muison, the Byrne family and LA group for their outstanding efforts on behalf of the Foundation.

This was a record year for fund-raising, demonstrating our vitality and determination. Together we raised nearly $20,000.

Again now and every day this year, thank you.

Grand Benefactor

Over $5,000
Los Angeles Support Group

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Joe Ann Neel
Karen Polak
Bellur Prabhakar, M.D.
Helene S. Reily
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Lillie Swanson
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Sonia Tramel
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Elizabeth Weinreb
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Edwin Wittenberg
David Wood
United Way (on behalf of employees at Xerox & Nestles)
Abdullah Zahid

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Florence L. Zelasko
Beverly Zell
It's now about nine months since we started up the PV Network in the UK, so it seems time to write something for the Foundation newsletter. As far as I know, this is the first network/support group that's been set up outside the United States, so it might be encouraging to anyone else who is thinking of doing the same in another country.

When I first developed PV in September 1995, I found, like many other people, that it was incredibly hard to get information. Luckily, I had friends who searched the Internet for me and found the American Foundation, which gave me the chance to be in contact with people who knew about it from the inside. At the same time, I started to find information from medical textbooks and libraries in England.

The germ of the idea to set up a network here started with friends who were appalled by how hard it was to find out anything. But, for the first year and a half I felt so ill that, though I thought it was a great idea, I knew I didn't have the energy to do anything about it.

Around March 1997 I thought things were getting better for me (complete fantasy actually, but that's another story) and my mind went back to the idea of creating some kind of 'branch' of the American Foundation. One of the friends who first suggested it felt able to help (Zoe's now one of the two other Network organisers) so we spent quite a lot of time knocking ideas back and forth and clarifying what we wanted to create.

Right from the start we had a strong feeling that less is more. We wanted to be a 'branch,' affiliated to the Pemphigus Foundation; a UK addition to its work, rather than duplicating things unnecessarily. Without Janet Segall and the American Foundation none of this would ever have happened, so really, the PV Network is the first Foundation 'baby.' We set out to make sure that no one in the UK ever again had such a tough time finding out about PV. We wanted to create a network where people with PV could contact other PV people if they needed to; a network that relatives and friends could use, and that, hopefully, doctors and nurses might find useful. Then of course the real work had to start: how to reach people with PV and how to publicize the Network.

At this time another friend living with PV, who became our other Network organiser, contacted me. This was great because she could input information about living with skin lesions. (Mine so far, has been mouth, nose and throat.) Together we can provide someone appropriate to whom people can talk if they need that.

Between the three of us, we have quite a few skills that helped us begin. Zoe's a very experienced medical editor and a wealth of contacts. Before I was ill I'd worked in publishing and was a practising masseuse and counsellor. I still had all my medical and drug reference books from past exams, though I never thought I'd be giving myself a crash course in immunology for beginners! Our other organiser was also a qualified counsellor and had worked in hospitals.

That's how we started and where we were in Spring 1997. What I hadn't expected was how incredibly hard it was to get ourselves known. I'd foolishly assumed there'd be one central database that doctors used, and that they would want to pass on information about a support group to patients who asked.

No such luck. After a lot of phone calls, letters and wrong avenues of enquiry, I managed to find a database that covers our National Health Service (though not many people have come to us from that source), and also registered us with every relevant database I could think of; e.g. the BBC national radio help line. At the same time, I wrote to the dermatology consultants we knew about who is specialising in blistering diseases. The British Association of Dermatologists (BAD) has been very helpful and supportive, and circularised their members about the PV Network. So far that hasn't led to many consultants telling their patients. I had good luck through the Dermatology Nurses' organisation, and this has led to quite a few enquiries.

I also managed to find several research and campaigning groups that try to raise the profile of skin disease in this country, and we've registered the PV Network with them. The Skin Care Campaign is particularly dynamic and has links with a special interest group within Parliament. Going to meetings should eventually raise our profile.

Our other avenue of activity had more initial success. With the advice of some friends who are press officers, I produced a press release which we sent off to a carefully selected list of medical journals and correspondents. We were very lucky and by August 1997 the Network had received a mention in the health pages of a national newspaper, plus two national women's magazines and a couple of specialist medical journals. The only problem was that I'd had a major relapse, was on 80 mg. of steroids and having a bad time!

Luckily, friends rallied round and photocopied some 'standard' letters I'd already written (covering most categories) which cut down the amount of typing I had to do. At one stage, I was getting about 40 letters a week from the national newspaper publicity and...
manically answering them through the night. Well, it’s one way to deal with complete insomnia and being a temporary speed freak! It has to be said that if friends hadn’t donated the cost of hundreds of pages of photocopying and postage for the press release, none of this would have been possible. Six months later, I am still getting enquiries from the newspapers, far more than from other sources, but at a steady pace. We also now get a steady flow of enquiries from nurses and care-workers. So far, there have been about 240 letters. Not all of them are from people with PV. Some people have Pemphigoid, and we let them know about a support group which already exists in England, though I’m always happy to talk to people on the phone. There have also been a fair amount of letters from people whose family or friends died from PV, often ten years ago, and they never managed to get any answers about the disease. It is enormously satisfying to be able to help them and realise we’re the first organisation in this country that’s been able to do so.

I still wish there was one simple way to reach all PV people here. But, that’s fantasy. The plan for this year is to gradually increase our profile amongst doctors, and liaise with skin campaigning groups to increase education about PV. Big aims, let’s hope we can get somewhere. I’m sure that our experience in setting up the Network has many similarities to the American experience. But there are some differences that I suspect are particular to the UK. One is how very few people who have written in have computers, email or Internet resources. I don’t have email or Net connections myself; can’t afford the running costs. Many people in the UK simply do not have computers at home, and of course, once you become ill you’re likely to become poorer and poorer. We’re currently all facing the possibility of having sick pay and disability allowances withdrawn. Also, I suspect that many people here who are elderly aren’t aware of where they could go to make Internet enquiries. It just isn’t part of their world. Therefore, it’s no good for the PV Network to rely on people finding us through the Internet. We have to be visible through more traditional means.

The other thing that may differ is how few people are willing to send stamps or give donations (however small) to cover paper and printing costs. Partly, it’s the downside of not currently being a registered charity. Also, because in the UK we pay for our National Health Service indirectly, it seems most people have an expectation that all health provisions and information should be free. If friends hadn’t helped and the American Foundation hadn’t given a contribution, I’d have had to stop the whole thing months ago.

But almost a year after starting, that’s my only personal gripe. I’d love it if more people felt able to formally ‘join’ the Network and thus make themselves available to new enquiries, but I can entirely understand that the majority of people simply want someone to talk to and answer their queries. Once that’s done, they prefer not to be involved.

I recently had a useful meeting with the public relations firms whose (free) services I can use via the Skin Care Campaign. They offered to do a brief press release on the setting up of the new website which they thought had every chance of being printed. Hopefully, this will be an indirect way for people here to find out about both the UK Network and the National Pemphigus Foundation.

To sum it all up so far, I think the three of us feel really pleased with how far we’ve gone, and we hope to be able to do far more in the future. If anyone from America is ever coming to London, do write and let me know—we’d love to meet up with you.

The Pemphigus Network
Flat C 26 St. Germans Road
London SE 23 1RJ England
Alternative theories

Food for thought: the blood type diet

by Steve Shapiro

Greetings! As usual, it’s been an exciting and educational three months. Those of you who have been following my articles may recall that I pledged to investigate every possibility, regardless of how remote, in my quest to live without pemphigus and the drugs used to control it. I am now happy to report that my research has uncovered a new therapy based solely on food choices. I have been following this program for the last eight months, with very promising and what should be repeatable results.

Have you ever wondered why some people gain weight or become ill while eating a supposedly healthy diet? Have you suspected that your pemphigus began after a viral/bacterial illness or injury? This theory, researched and presented by Dr. Peter D’Adamo in his book Eat Right 4 Your Type, explains both of these phenomena; and offers a plan for reversing the cause of the illness.

What is blood type? Blood type is the most powerful and obvious genetic inheritance we have. For the terms of our discussion, it is important because it is one of the primary ways by which the immune system identifies “self” from “non-self.” Every cell of our bodies has the blood type marker (called an antigen) on it. If the immune system sees something without this marker an attack response is started.

The food connection: simply put, the blood type theory states that food items are identified as being healthy or harmful based on the blood type of the individual. This explains why a food that appears to be healthy for one individual or group of individuals causes illness in another individual or group. It also explains one mechanism by which the autoimmune disease process starts (pemphigus is an autoimmune disease) and offers a solution for stopping it.

A chemical reaction occurs between your blood and the foods you eat. This reaction is part of your genetic inheritance. Lectins, abundant and diverse proteins found in foods, have agglutinating properties. The term “agglutinate” shares the same root as the term “glue,” meaning a substance that holds other substances together. Lectins are a powerful way for organisms in nature to attach themselves to other organisms. Similarly, they can also affect your blood and body tissues, causing them to become “glued together.”

There are several mechanisms by which agglutination, or clumping, damages our bodies. In the blood, each red blood cell is normally repelled from neighboring red blood cells by a small negative electrical charge. This is necessary as blood cells must proceed single file through narrow capillaries in order to nourish our body tissues.

If the red blood cells are agglutinated, they may occlude, or block off, small arterioles and capillaries in our tissues. The tissue cells downstream from the occlusion will be temporarily starved and sit in their own waste products.

If this occlusion happens in a gland, such as the thyroid or adrenal glands, it sets the stage for malfunction within that gland. Succinctly, the gland will not do its job of producing and releasing the proper hormones and metabolites necessary for subsequent reactions [Diagram 1].

When you eat a food containing protein lectins that are incompatible with your blood type, the lectins target an organ or bodily system (such as our skin) and begin to agglutinate (or clump) cells in that area. This process may identify these cells as ‘non-self,’ thus targeting them for attack by the immune system.

Many food lectins have characteristics that are close enough to a certain blood type antigen to make them an enemy to another blood type. For example, cow’s milk has B-like qualities; if a person with type A or type O blood drinks it, his system will immediately start the agglutination process in order to reject it [Diagram 2].

The viral/bacterial connection: lots of germs, and even our own immune systems, use the lectin superglue to their benefit. For example, cells in our liver’s bile ducts have lectins on their surfaces to help them snatch up bacteria and parasites. Bacteria and other microbes have lectins on their surfaces as well, which work like suction cups so that they can attach to the slippery mucosal linings of the body.

Often the lectins used by viruses or bacteria can be blood type specific, making them a stickier pest for people of that blood type. In an attempt to evade our immune systems, the virus/bacteria may take on an appearance similar to tissues of our own blood type. Our immune system, when it eventually recognizes this invader, may become confused by this similarity, and mistakenly attack our own tissues.
The trauma connection: it has been demonstrated that red blood cells and other tissues become agglutinated after sustaining an injury. It is possible that the immune system targets these cells for destruction and then mistakenly goes on to attack similar healthy tissue.

Putting it all together: to put it mildly, this is a controversial subject and this non-technical article only addresses a limited scope of the topic. Dr. D’Adamo’s work has been both praised and criticized, and it is very misunderstood. It is not possible to do double-blind or placebo controlled studies with long term diet therapies and illnesses that do not have a direct cause and effect relationship.

This moves the evidence for this theory into anecdotal circles, with one important distinction. Many people with incurable, potentially fatal illnesses such as pemphigus have been helped by following this eating plan. Furthermore, choosing foods in this manner has no side-effects, and if one eats from a variety of the permissible foods for their blood type, there is no danger of malnutrition.

This is an important distinction from drugs and many natural therapies, which can have side effects associated with them. In addition, there are no fees or required products to purchase.*

Choosing foods by blood type is a long term solution. Rather than acting to suppress the symptoms, it corrects the underlying cause of the illness. Thus, it may take several months of following the program to see any change in one’s health, and many more months before disease symptoms start abating. During this time, continuing current medications (if any) and other supportive therapies is indicated.

How to start: if you would like to start helping yourself by choosing foods by blood type:

1. You will need to know your blood type: A, AB, B or O.
2. You may wish to read Dr. D’Adamo’s book, Eat Right 4 Your Type. It is available from most major booksellers, and many libraries have a copy.
3. You may want to get a list of foods to eat and avoid, based on your blood type. You may construct a list by going through the book, accessing the Internet, (Dr. D’Adamo’s web site is http://www.dadamo.com) or send me 2 stamps and your blood type. I’ll send you a nicely formatted copy of the food list for your blood type. If you would like additional lists for other family members, add one stamp per list and indicate which list(s) you would like.

* If, after 6 months, you are noting some success with the program, there are several lab tests that can help fine tune your food choices for maximum healing.

Editor’s note: Mr. Shapiro is not a licensed physician. His views are his own and provided here for information only.

The National Pemphigus Foundation is not connected with Dr. Peter D’Adamo. Discuss your individual medical situation with your physician.

**NIAMS Day**

Continued from page one

"Autoimmune diseases comprise the third largest group of disease sufferers, behind heart disease and cancer; over 10 million Americans are in this group, requiring $86 billion in health care funding annually," said Segall after the meeting. “We discussed the definition of autoimmunity and the tendency of this group of diseases to run in families. We talked about researchers and physicians working together to eradicate all autoimmune diseases. There were some very promising ideas discussed here, and joining our forces will only help all of us involved.”

**NIH budget increase urged**

As a member of the Coalition for Patient Advocacy for Skin Disease Research (CPA SDR), the National Pemphigus Foundation was invited to speak before the U.S. Congressional Budget Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies on February 4, 1998.

The NPF joined forces with other members of the CPA SDR to request a 15% increase in the National Institute of Health (NIH) budget. Eighteen speakers from 14 organizations, including Critical Care Nursing, Multiple Sclerosis and the American Cancer Society, presented testimony. The reception of the speakers by committee chairman, Representative John Porter of Illinois was most cordial.

**Crossfield to guide promos**

On her recent trip to Washington D.C., NPF President Janet Segall met with Carey Crossfield from Nutter & Harris, a government relations and public affairs firm. Crossfield has offered to assist the Foundation in establishing a presence in Washington and publicizing the Foundation. Erica Byrne of Baltimore, Maryland will act as the Foundation’s contact in Washington.

Crossfield suggested the NPF establish a “Pemphigus Awareness Day” and contact state representatives. She also provided a packet of sample press releases.
The sticky subject of bandages

by Milo Careaga

Lesions can and do appear anywhere. They often start as blisters, but quietly turn into raw, open sores which need covering. Treating these wounds is no different than treating burns. We all have the same basic concerns. This article presents what worked for me.

Infection. Infection is the number one worry and should supersede all other concerns. Infection can increase the time needed for healing and even cause life-threatening complications. Also, because our disease is immune-stimulated, infections might lead to more skin activity.

Keep the wounds clean. Wounds should be cleaned once or twice a day. Water is the absolute minimum, but a diluted bleach and water mix is suggested. Do not use harsh cleansers or iodine, and do not scrub too hard. All of these can cause more damage. Bathing and whirlpool baths are best. Soaking helps remove debris, scabs and dead skin.

Ointments and creams. Antibiotics ointments are often required to prevent or treat infection. Neosporin is a good antibiotic ointment for simple sores, but it is thought long-term use may induce an allergy. Bactrahan is the prescription equivalent and works much better.

Both can be expensive and time-consuming in treating large areas. A cream like sulfa salvinone (available from your doctor) might be used better here.

Keeping wounds moist. Yes, this sounds like what you would not want to do, but keeping wounds moist is a must for healing. Vaseline, aquaphor, or the above creams and ointments can help. Also, some bandages do the job, but be alert for infection because moisture creates a breeding ground for bad stuff.

Vaseline impregnated gauze comes prepackaged. It is relatively cheap, comes in large sizes, and works quite well. For large areas and for home use, this might be the best.

Best bandages. Silicone bandages. Burn wards have been using silicone bandages for years. These are bandages made of silicone and water. They provide moisture, protection and are easy to remove. They are by far the best thing for burns. They are, however, expensive and many health care programs don’t cover bandages at all.

Vigilon is the name of the bandage hospitals use. It comes in various sizes. Vigilon is a medical bandage, and can probably be ordered though your local pharmacy. You can also find it in some camping and dance stores. Larger sizes of this product come labeled as “sterile,” but if you use them with antibiotics it should be okay. I have been able to find patches up to 6x8 inches which come in sterile packaging.

Second Skin is the brand name of a product like Vigilon. It comes in lots of sizes, but I found it very hard to find the large sizes in camping or dance stores.

Mepitel is a newer silicon bandage which can be washed and reused. It is available from Scott Health Care, 140 Gardner Pl., Danville, CA 94526, 800-992-9939, extension 3.

Anticoat is a brand new bandage that has the antibiotics in it, but it is not yet on the market.

I hope this helps you.

Note: Mr. Careaga’s experience on this subject is extensive, but your situation may be different.

The fine art of bathing

A modified Dakin’s solution bath is good infection prevention, and useful at bandage changing time. This consists of two teaspoons of household chlorine bleach mixed with one gallon of water. For 20 gallons of water, enough to partially fill an average size bathtub, you need about seven ounces of bleach. Mix it into the bath water before you go in. Soak in the bath for 15 to 20 minutes. If you are using bandages that tend to stick, enter the bath with those bandages that cannot be easily removed. After the bath, they should come off easily.

The modified Dakin’s soak can be used everyday or three times a week, with plain water baths on the other days. After soaking, very gently clean healing wounds with plain water and a washcloth. Take care not to scrub too vigorously or you will remove the healing areas of skin.

It is good to apply Vaseline or something similar to the wounds and dry area to promote healing.
Coffee, stress and Prednisone deplete potassium

by Hannah Lisa Reade

Since Prednisone may cause a loss of blood potassium, here are some facts about this mineral.

What it does: potassium helps prevent stroke, aids proper muscle contraction and, with sodium, controls the body’s water balance. It is important for stabilizing blood pressure, and regulating the transfer of nutrients through cell membranes. This transfer of nutrients has been shown to decrease with age.

Deficiency: signs are very dry skin, glucose intolerance, low blood pressure, edema, weakness, protein in the urine, muscle cramps, tiredness, diminished reflex function, depression and fluctuation in heartbeat.

Alcohol, coffee, sugar, diuretics, low carbohydrate diets, mental and physical stress can all cause deficiencies.

Dietary allowance: none has been set, but 1,600 to 2,000 mg daily is considered sufficient for healthy adults. An intake of 18 grams can cause toxicity.

Natural sources: baked potatoes with the skin (one seven-ounce has 844 mg.), avocado, beet greens and leafy greens, baked beans, tomatoes, sardines, lima beans, carrots, bananas (one has 451 mg.), fresh orange juice, swordfish, acorn squash, sweet potatoes, almonds and soybeans.

REFERENCES:


Disclosure: Dr. Anhalt and Dr. Nouari have no financial interest in the manufacturer of Cellecept or Roche Pharmaceuticals, and have received no compensation for its development or promotion.
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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Apples for the treatment of pemphigus vulgaris

by Robert Fitman, M.D.
March 17, 1998

The pemphigus disorders are a group of serious and potentially life-threatening diseases characterized by the formation of cutaneous and mucosal blisters. An autoimmune process is believed present which is directed against keratinocyte desmosomal components resulting in a loss of intercellular adhesion (1).

Systemic corticosteroids remain the mainstay of therapy for pemphigus, transforming an invariably fatal disease into one whose mortality is now below 10%. Because of the serious side-effects of long term corticosteroid therapy, there have been efforts to use other drugs such as Imuran, Cyclosporin and Dapsone (2). We report a case of pemphigus vulgaris in which reduction of symptoms was obtained by the addition of apples or apple juice to the daily diet.

Report of a case: a 59 year old Caucasian male noted soreness of the tissues of the mouth of rather sudden onset. The dorsal surface of the tongue as well as the left and right buccal regions were most severely affected. Lesions of these regions appeared in response to the slightest trauma, for instance the chewing and swallowing of bread with a firm crust. Eating became difficult and a soft diet was adopted.

After elimination of common oral cavity problems such as thrush, herpes stomatitis and other viral infections, a biopsy of the buccal mucosa was performed and submitted for histopathological examination. The microscopic examination suggested pemphigus. The diagnosis of pemphigus vulgaris was confirmed by immunofluorescent antibody techniques and later, by the demonstration of the presence of the appropriate circulating antibodies of pemphigus.

Treatment was begun with Prednisone at a dosage of 60 mg. per day. There was a rapid reduction and then elimination of symptoms. The dosage was reduced to 20 mg. of Prednisone daily but symptoms of the disease appeared if the dose of Prednisone was reduced below this. After approximately one year of treatment, the well known side effects of steroid therapy began to appear. Hypertension, mild diabetes, cataracts and muscle weakness and wasting developed. In an effort to decrease the dependence on steroids, therapy with Imuran (50 mg. BID) and with Dapsone (gradually built up to 100 mg. BID over three months while monitoring liver enzymes as well as the CBC) was begun.

There was no evidence of liver damage. The SCOT and SGPT levels remained normal. There was a reduction in the hematocrit and hemoglobin levels to the low normal range and an increase in the reticulocyte count. These changes were anticipated and are consistent with the fact that Dapsone shortens the RBC survival time.

The dosage of Prednisone remained at 20 mg. per day while the dosage of Dapsone was increased gradually to 100 mg. BID. After two months at this level of Dapsone, the dosage of Prednisone and Imuran was gradually reduced to zero with only minimal symptoms of pemphigus noted. The dosage of Dapsone was maintained at 100 mg. BID.

At this time, the patient reported that the addition of apples to his diet appeared to produce a reduction in the symptoms of pemphigus. It was decided to test this by adding three apples each day to the diet of the patient. There appeared to be a beneficial result. Finally, Dapsone was completely eliminated and the only treatment given was three apples each day. The symptoms of pemphigus were completely controlled. After three months of three apples daily as the only treatment for pemphigus, the patient remains symptom free. The patient reports that apple juice (200 cc. per apple) may be substituted for apples with the same beneficial effect. If apples and/or apple juice are eliminated from the diet, the patient reports that the symptoms of pemphigus reappear in two or three days.

Comment: pemphigus is a group of diseases which include pemphigus vulgaris, the most common form, as well as pemphigus vegetans, pemphigus foliaccus, pemphigus herpetiformis, drug induced pemphigus and paraneoplastic pemphigus. The severity and natural history of the disease is variable (1). It is impossible to draw any general conclusions from this single case.

However, the use of apples in the treatment of pemphigus, at least in this patient, appears to be effective and free of harmful side effects. Only after the experience of many practitioners is recorded can there be any evaluation of the use of apples in the treatment of pemphigus in its many forms and degrees of severity.

The addition of three medium sized apples to the daily diet is suggested. The variety of apple appears to be irrelevant. Apple juice may be substituted for apples at the rate of 200 cc. or approximately 7 oz. per apple. If the experience of other practitioners confirms the usefulness of apples in the diet of pemphigus vulgaris patients, the question of the identity of the active ingredient(s) becomes of interest. While one can speculate on this question, the powerful methodology of modern chemistry will certainly provide the answer in a rapid fashion.

References:

Note: The information provided in the above article is obtained from a single case observation. This must be viewed as anecdotal evidence, not evidence that has been provided by the observations of a large number of patients. I am not giving medical advice to any patient nor am I advising any patient on a course of treatment.

Treatment of pemphigus vulgaris, as treatment for any disorder, can only be given by the patient's personal physician. If you suffer from pemphigus, I urge you to print this article and show it to your physician. In particular, it must be stressed that alteration in the dosage of any prescribed medication must be done only on the advice of one's physician.

This is true of any prescribed medication but is especially true of steroid medication.
...Dermatologists enjoy AAD

Continued from page one

The first national meeting of the NPF is scheduled for August 1, 1998 in Chicago, Illinois. A “Get Acquainted” Brunch will be hosted by the Foundation at the Hyatt.

The evening event, which features Dr. Grant Anhalt of Johns Hopkins and other experts on pemphigus, will take place in a restaurant near the Hyatt. The location has yet to be finalized.

Enclosed in this issue of the Newsletter is a flyer with further information about reservations.

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