Diversity of pemphigus reflected in survey results

By Sal Capo
Director of Communications

We are delighted with the response to our first International Questionnaire on pemphigus. The report of our survey begins on page six. Seventeen questions, some with multiple parts, were included in the Spring issue which was mailed out in February 1999.

Survey forms were collected until June 1999. Questionnaires were returned by 166 patients. Five forms arrived damaged or otherwise unreadable, and two arrived too late to count. The total counted was 158. The results for the last five questions, which concerned eye involvement, will be presented at a later date.

Two thirds of our replies were from women, and 21.5% came from outside the United States. While there were no shocking surprises, several interesting points were raised, and various lessons were learned to improve the next questionnaire.

Among the noteworthy results are that dermatologist misdiagnose women twice as often as men, pemphigus is usually controlled in 10 to 12 months and diabetes strikes those on Prednisone twice as often as the general public.

We are interested in your comments about the survey. Please direct them to the NPF office. The address is on page two.

Two vacancies open on Board of Directors

Jean Barish, president of the NPF, announced that two members of the Board of Directors have resigned.

Carolyn Rodis, Secretary; and Robert Mufson, East Coast Fund-raising Chairman, resigned for personal reasons. Rodis resigned in August and Mufson in September.

“Both Carolyn and Bob were valuable members of the Board who came at a critical time,” said Barish. “They helped get us through some important projects and we will miss their contributions.”

Both Rodis and Mufson joined the Board in May 1998. Nominations are presently being taken for these positions.

The Hayden Report

Wrestling over healthcare issues

By Cheryl Hayden
Lobbyist for the American Academy of Dermatology

Despite the reservations of the Congressional Leadership, managed care reform legislation has passed in both the House and the Senate and efforts are underway to begin the process of reconciling the numerous differences between the two bills. The fact that this legislation has progressed this far is a point of some amazement to “inside the Belt-way” pundits, who believed the legislation dead after the Senate passed a watered down version of health care reform this summer.

Although many believe that health care reform is a bipartisan issue, it has never been viewed as such within the walls of the Congress. Starting in 1993 with the introduction of the Clinton health plan, this has been an issue that has played out in cutthroat partisan fashion. Even the 1996 Kennedy/Kassebaum bill, which is viewed as a bipartisan success story, almost did not come to pass because of partisan wrangling.

On July 15th, the Senate passed S. 1344, “the Senate HMO Protection Act.” The Senate bill was the work product of Senators Don Nickles and Trent Lott, who are rather famous for their opposition to health care reform.

S. 1344 is a rather modest bill, applying only to the estimated 48 million Americans enrolled in self-insured health insurance plans, also known as ERISA plans. The Senate bill did not include any address of the most controversial issue in managed care reform - a patient’s right to sue his/her managed care plan for malpractice. It does contain language providing for both internal and external appeals for coverage decisions, a limited prescription drug formulary, access to clinical trials for cancer patients and a very modest point-of-service option.

From the beginning, the Senate debate on health care reform was a highly charged partisan affair. To ensure success for their plan, Senate Republican Leaders carefully structured debate.

The Democratic substitute Kennedy/Daschle managed care bill was used as the “base bill,” a highly unusual step. Dozens of amendments were made, the most important of which was the final amendment, a substitute bill, S. 1344.

During the week that the Kennedy bill was debated on the floor, patient and physician advocates worked hard to ensure passage of a number of key amendments, in the hope that Continued on page 13
If we raise more, we can do more

At the conference this year our Board President, Ms. Jean Barish, presented her ideas on how we can all become involved in fund-raising. We reported them in the last newsletter. We have sent out our Annual Holiday Fund-raising packets and we hope you will join us in our efforts to keep this Foundation in the black.

Let me first remind everyone what we provide and what we want to see for our future. Since there is limited data available on pemphigus and pemphigoid, our newsletter provides the most up-to-date medical information, a section that includes names and phone numbers for those who need support from others, and personal stories that give us hope and often uplift our spirit. For those people with access to the Internet we provide the most comprehensive data on pemphigus and pemphigoid available. We have links to other sites that are relevant to our health, nutritional information and much more. We provide an online support group so people can converse with one another regarding important issues dealing with pemphigus or pemphigoid.

We provide referrals to doctors who specialize in bullous diseases, and our Medical Advisory Board consists of world-renowned dermatologists who have given their time and support to our organization’s goals and objectives. Besides the physicians on our Medical Advisory Board, there are many others who have given their time and support to us as well.

Our membership in the Coalition for Patient Advocacy for Skin Disease Research has given us the opportunity every year to attend the American Academy of Dermatology’s conferences. At these conferences we connect with doctors interested in our diseases from all over the world. This year I met doctors from Hong Kong, South Africa, and Iran. Every year this group goes to Washington to meet with congressional members, to remind them how important research is for us. Once we got to testify in front of Congress.

Our organization means a great deal to many people, and the truth is, we are in great financial difficulties. We need to raise a minimum of $70,000 to keep us running as we have been. If we can raise more, we can do more. Recently I received a call from a friend living with pemphigus. She was frantic because she had not received her newsletter and she thought we had gone out of business. She expressed to me how that terrible lonely feeling came back to her — the feeling she had before she knew we were here; like she was the only one.

So, we ask you to support our effort during this holiday season. Ask or write to your friends, relatives, co-workers. Use our letter or write one of your own. Four hundred people sending out requests for $10 or $20 to 10 people will help us substantially. Put a jar on your desk at work, as I did at my brother’s volleyball sports club. Ask your employer if they have a matching gift program. Avoid capital gains tax and deduct the entire amount as a charitable contribution by donating shares of stock. Have a bake sale or a car wash. Involve your kids. Throw a dinner, or if someone you know plays an instrument have a concert. Charge $50 and enjoy

Continued on page 16
TheNeedforAlternativeTherapiesforPemphigus. In auto-immune pemphigus, systemic glucocorticosteroid treatment is life saving but may cause severe side effects. Pemphigus patients therefore need drugs that will provide safer treatment of their disease by replacing systemic use of glucocorticoid hormones such as Prednisone. Development of non-hormonal treatment is hampered by a lack of clear understanding of the mechanisms leading to pemphigus lesions. Pemphigus can be associated with myasthenia gravis, and in both diseases the autoantibodies to acetylcholine receptors are produced, suggesting a common mechanism of disease development.

First experience of treatment with Mestinon and azathioprine without systemic glucocorticoids. In a 33-year-old female patient from New York, pemphigus vulgaris developed on the background of myasthenia gravis which was treated for approximately four years with the cholinergic drug Mestinon and a topical glucocorticoid cream. During worsening, azathioprine was added and the treatment was continued without need for using systemic glucocorticosteroids. The intriguing aspect of management of this patient is that the conventional glucocorticoid therapy has never been instituted. Although it is possible to maintain pemphigus patients in remission using immunosuppressive drugs only, initial treatment of pemphigus vulgaris usually relies on the high dose of systemic glucocorticoids. Since control of pemphigus in this patient was achieved without using systemic glucocorticoids, Mestinon should be considered as a therapeutic agent that could ameliorate the natural course of pemphigus.

How could Mestinon ameliorate pemphigus? Mestinon inhibits the destruction of acetylcholine by acetylcholinesterase and thereby permits stronger adhesion of the skin cells keratinocytes. Acetylcholine competes with the disease-causing pemphigus antibodies preventing them from attachment to keratinocytes, and reverses pemphigus antibody-induced detachment of keratinocytes in cell culture. Although it has been postulated that pemphigus vulgaris is caused by autoantibodies to the adhesion molecules desmogleins 1 and 3, the results obtained in my research laboratory show that the pool of disease-causing pemphigus antibodies includes the autoantibodies to keratinocyte acetylcholine receptors in approximately 85% of patients.

An opportunity to test the therapeutic efficacy of Mestinon in pemphigus. Each Mestinon tablet contains 60 mg of the reversible acetylcholinesterase inhibitor pyridostigmine bromide, which is used to treat muscle weakness in patients with myasthenia gravis. Pyridostigmine bromide is FDA approved for use in myasthenia gravis, but is experimental for the treatment of patients with pemphigus without myasthenia gravis. The Human Subjects Review Committee of University of California-Davis has recently approved the protocol of clinical trial of Mestinon in pemphigus. The study will be conducted in my dermatology clinic at the University of California-Davis Medical Center in Sacramento. Upon my request, ICN Pharmaceuticals has furnished Mestinon tablets for this clinical trial.

Description of the clinical trial of mestinon in pemphigus. The preliminary trial will be carried out in a limited number of patients with acute pemphigus vulgaris and pemphigus foliaceous. If the results are encouraging, we will extend the trial. Patients who are willing to participate in the study will not receive the standard treatment for pemphigus. Instead, they will receive Mestinon tablets orally from one to six per day, that is from 60 to 360 mg of pyridostigmine bromide per day. The dose of Mestinon will be adjusted for each particular patient based on his or her response to treatment. Experience with the use of Mestinon in myasthenia gravis patients indicates that failure of patients to show clinical improvement may reflect underdosage, by analogy with a lack of therapeutic effect of low-to-mid doses of Prednisone in acute pemphigus vulgaris.

Adverse reactions to Mestinon and contraindications. The side effects of Mestinon are most commonly related to overdose. These side effects may include nausea, vomiting, diarrhea, abdominal cramps, frequent passing of flatus and/or a need to have a stool, increased production of saliva, increased bronchial secretion, excessive sweating, muscle cramps and twitching, and muscle weakness. Mestinon is contraindicated in mechanical intestinal or urinary obstruction, and in patients with bronchial asthma.

If you are willing to participate in the clinical trial of Mestinon in pemphigus, you may inquire about enrollment eligibility by contacting me by telephone (916/734-6037), or by email (sagrando@ucdavis.edu) or by letter (Dr. Sergei A. Grando, UC Davis, Department of Dermatology, Ambulatory Care Center, 4860 Y Street, Suite #3400, Sacramento, CA 95817).
Los Angeles

By Carol Goren

The Los Angeles chapter met on October 17, 1999. 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 conference and stated that some of the best doctors in the country participated, including Dr. Brenner who discussed her food research. She feels there is a correlation between food and lesions. Janet also stated that they were planning a one day seminar in San Francisco, targeted for October 2000. Doctors and specialists would participate.

The annual fund raising campaign will begin in November and run through December. Packets will be sent out to all members. It is hoped that members will make a personal contribution, contact friends, family and businesses. Suggestions for additional fund raising ideas included an auction or dance. Members had an opportunity to share and asked that a list of doctors knowledgeable regarding pemphigus be developed for Southern California.

The next meeting will take place in February or March. It is hoped that Dr. Woodley, a USC doctor, specializing in bullous diseases, will address the group.

Contact: Barbara Roller
Phone: 818-991-6569
Email: barby43@aol.com

San Francisco

Contact: Janet Segall
Phone: 510-527-4970
Email: pvnews@aol.com

Houston

Contact: Richard M. Schwartz
5231 Kinglet St.
Houston, TX 77035
(H) 713-723-5647
(W) 713-721-1178
Fax: 713-726-0286
Email: richardm@hal-pc.org

Midwest

Contact: Arlene Strauss
514 Inverness Lane
Deerfield, IL 60015
Phone: 847-808-9188
Email: ChicagoP@webtv.net

Philadelphia

Contact: Barbara Sipe
Phone: 215-662-6446

Baltimore

Contact: Erica Byrne
4610 Learned Sage
Ellicott City, MD 21042
Phone: 410-964-1099
Email: byrnete@erols.com

Toronto

By Dan Goodwill

Our next local group meeting will take place on Sunday, November 7 at 2 PM. It will be held at our usual location, the Activity Room, Second Floor - track level, North Toronto Memorial Community Centre, 200 Eglington Avenue West. I will send out a reminder notice just prior to the meeting date. As requested, I will try to schedule one meeting early in the New Year and one next Spring. I will confirm the dates in the future.

Contact: Dan Goodwill
105 Hillhurst Blvd.
Toronto, Ontario, M5N 1N7 Canada
Phone: 416-488-0453
Email: danxgail@ican.net

New York

By Joan DeLucie and Matt Koenig

The New York group met on Tuesday, September 15, at NYU. We heard a presentation on nutrition from Dr. Riva Touger-Decker, the Dental School program director from the University of Medicine and Dentistry of New Jersey.

Dr. Decker spoke strongly about the benefits of a proper and complete diet with supplements in maintaining health for those with pemphigus. She also provided a great deal of information on osteoporosis and the importance of calcium intake. There were lots of questions and personal war stories regarding the best methods of maintaining and improving calcium levels. It became clear that everyone needed to take an active role to insure their own adequate calcium intake.

We also discussed the food pyramid in depth, and the relevance of the current reduced carbohydrate diet plans. I pointed out that the pyramid had a fat bottom, caused by too many carbohydrates. Dr. Decker assured us that portion size is the key, and that even though the pyramid indicates 6-11 servings of carbohydrates daily, each serving was actually quite small (like 1 slice of bread, 1/16 of a piece of cake, or a half cup of pasta).

Of course, all this talk made every-
...New York Group Hear About Diet and Nutrition......

one hungry. Refreshments included fruit salad and homemade crumb cake. Both were delicious. We all agreed that we would start worrying about carbohydrates at the NEXT meeting. It will be a general membership meeting, with topics of discussion to include our plans for a golf outing in May, and our upcoming annual fund raising efforts.

Our next meeting will be Thursday, November 11, 1999 at 5:30 PM, New York University Medical Center, 560 First Avenue, Tisch Hospital Building, Skin Clinic, Main Lobby, Orentreich Conference Room.

PLEASE NOTE: Dr. James Rasmussen and Dr. Joyce Rico will attend the November meeting. Dr. Rasmussen will give a brief update on Peptimmune’s research protocol and answer any questions you may have. Once again, they are asking the NY group for volunteer blood donors. Please let me know if you would like to participate. Dr. Rico has made all the appropriate arrangements for a nurse to draw our blood in a private room. Check your mailbox for the announcement and please RSVP via email or phone. Thanks, see you then.

Contact: Joan DeLucie
9 Mehan Lane
Dix Hills, NY 11746
Phone: (516) 586-6910
Email: jdelucie@aol.com

Contact: Matt Koenig
88 East Valley Stream Blvd.
Valley Stream, NY 11580
Phone: (516) 825-4594
Email: mattkoe@aol.com

The NPF Website
Sal Capo, Webmaster

Miss an article? Want a link to a medical dictionary? Check out our website, located at www.pemphigus.org. And let us know if you have comments or suggestions.

Online Support
Sandra Frank & Sal Capo, Managers

The National Pemphigus Foundation
Online support group is open to everyone interested in pemphigus.

To join the list send a blank message to discussion-on@pemphigus.org. No other information is required, nor will it be posted, because a computer handles this part of the process. Your email address will then be added automatically and you should get a welcoming message within 24 hours. If you do not, contact Sandra Frank at sfrank1010@aol.com.

Dallas/Ft. Worth
Contact: Angela Vickers
5511 Calvary Post Drive
Arlington, TX 76017
817-557-9642

Got Shirts?

T-SHIRTS $15.00 each, adult sizes only.
Back: Please Support the National Pemphigus Foundation
__ XL ___ XXL ___ Quantity ___

BUMPER STICKERS $2.50 each, white on blue Quantity ___

BUTTONS $2.00 each, 2” round, blue metal-flake color “Support the National Pemphigus Foundation” Quantity ___

Total amount enclosed $______

Copier with Prednisone by Zukerman & Ingelfinger

If you live overseas and previously could not get this important book, now you can.
Just send $30.00 (U.S. funds only) to the NPF at the address below and a copy will be sent to you.

Awareness Program

NAME: ____________________________

ADDRESS: ____________________________

CITY: ____________________________

STATE/COUNTRY: ____________________________ POSTAL CODE: ____________________________

Copy or cut out this form, return with check or money order (U.S. funds only) please to: Merchandise, The NPF, Box 9606, Berkeley, CA 94709-0606. All prices include shipping.
NPF International Survey results

1. Number and sex of respondents, breakdown by disease classification. Pemphigus is generally believed to be one autoimmune disease which strikes men and women equally, but twice as many women as men responded. Do women respond to surveys more often than men? According to Dr. Grant Anhalt, PV cases outnumber PF by five or six to one in his experience, but in our survey, the spread was close to 12 to one.

<table>
<thead>
<tr>
<th></th>
<th>U.S. Males</th>
<th>NON-US Males</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>PV</td>
<td>33 20.80%</td>
<td>11 7.00%</td>
<td>44 27.80%</td>
</tr>
<tr>
<td>PF</td>
<td>2 1.30%</td>
<td>1 0.60%</td>
<td>3 1.90%</td>
</tr>
<tr>
<td>BP</td>
<td>3 1.90%</td>
<td>0</td>
<td>3 1.90%</td>
</tr>
<tr>
<td>CP</td>
<td>1 0.60%</td>
<td>1 0.60%</td>
<td>2 1.30%</td>
</tr>
<tr>
<td>Totals</td>
<td>39 24.70%</td>
<td>13 8.20%</td>
<td>52 32.90%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>U.S. Females</th>
<th>NON-US Females</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>PV</td>
<td>72 45.60%</td>
<td>20 12.70%</td>
<td>92 58.20%</td>
</tr>
<tr>
<td>PF</td>
<td>8 5.00%</td>
<td>0</td>
<td>8 50.60%</td>
</tr>
<tr>
<td>BP</td>
<td>4 2.50%</td>
<td>1 0.60%</td>
<td>5 3.20%</td>
</tr>
<tr>
<td>CP</td>
<td>1 0.60%</td>
<td>0</td>
<td>1 0.60%</td>
</tr>
<tr>
<td>Totals</td>
<td>85 53.80%</td>
<td>21 13.3%</td>
<td>106 67.10%</td>
</tr>
</tbody>
</table>

TOTAL US = 124 (78.5%)
TOTAL NON US = 34 (21.5%)

2. What is your age now and your age at the onset of disease?

The average age of our respondents at the time of the survey:

<table>
<thead>
<tr>
<th></th>
<th>US</th>
<th>NON-US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>57.8</td>
<td>55.4</td>
</tr>
<tr>
<td>Female</td>
<td>54.8</td>
<td>56.8</td>
</tr>
</tbody>
</table>

The average age of our respondents at the time of the onset of disease:

<table>
<thead>
<tr>
<th></th>
<th>US</th>
<th>NON-US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>53.4</td>
<td>57.8</td>
</tr>
<tr>
<td>Female</td>
<td>47.9</td>
<td>52.8</td>
</tr>
</tbody>
</table>

The average span of illness per respondent:

<table>
<thead>
<tr>
<th></th>
<th>US</th>
<th>NON-US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>4.4</td>
<td>3.4</td>
</tr>
<tr>
<td>Female</td>
<td>6.9</td>
<td>4.0</td>
</tr>
</tbody>
</table>

Abbreations:

PV = pemphigus vulgaris
PF = pemphigus foliaceus
BP = bullous pemphigoid
CP = cicatrical pemphigoid
M = male
F = female
3. Where were you born?

<table>
<thead>
<tr>
<th>MALES</th>
<th>FEMALES</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>US</td>
</tr>
<tr>
<td>Canada</td>
<td>Canada</td>
</tr>
<tr>
<td>Africa</td>
<td>South America</td>
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<tr>
<td>Subcontinent</td>
<td>Middle East</td>
</tr>
<tr>
<td>Western Europe</td>
<td>Western Europe</td>
</tr>
<tr>
<td>Eastern Europe</td>
<td>Eastern Europe</td>
</tr>
<tr>
<td>Pacific Islands</td>
<td>Asia</td>
</tr>
<tr>
<td></td>
<td>Australia/N.Zealand</td>
</tr>
</tbody>
</table>

4. What is your ethnicity? There is no race or group of people on earth free from pemphigus. We know from previous studies that certain groups are affected by pemphigus more than others. For example, counts in Israel done by Dr. Sarah Brenner put the rate of pemphigus between 1.6% and 2.2%, and Dr. Luis Diaz reports that certain native tribes in Columbia and Brazil have rates as high as 30% for the fogo selvagem variant of pemphigus foliaceus. In our survey, Occidentals (white, non-Jewish) men numbered 35% of our total headcount while Occidental women made up 42%. Jews consisted of 46% of total men and 42% of women.

<table>
<thead>
<tr>
<th>US</th>
<th>NON US</th>
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<tbody>
<tr>
<td>Amer./Alaska native M</td>
<td>F</td>
</tr>
<tr>
<td>PV</td>
<td>PF</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td>M</td>
</tr>
<tr>
<td>PV</td>
<td>PF</td>
</tr>
<tr>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Black (non-Hispanic)</td>
<td>M</td>
</tr>
<tr>
<td>PV</td>
<td>BP</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>East Indian</td>
<td>M</td>
</tr>
<tr>
<td>PV</td>
<td>BP</td>
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<tr>
<td>2</td>
<td></td>
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<td>Hispanic</td>
<td>M</td>
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<td>PV</td>
<td>BP</td>
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<td>1</td>
<td>3</td>
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<td>Jewish</td>
<td>M</td>
</tr>
<tr>
<td>PV</td>
<td>BP</td>
</tr>
<tr>
<td>18</td>
<td>1</td>
</tr>
<tr>
<td>34</td>
<td></td>
</tr>
<tr>
<td>Occidental</td>
<td>M</td>
</tr>
<tr>
<td>PV</td>
<td>BP</td>
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<tr>
<td>10</td>
<td>1</td>
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<td>30</td>
<td>4</td>
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<td>Pacific Islands</td>
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<td>PV</td>
<td>BP</td>
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<tr>
<td>Arab</td>
<td>M</td>
</tr>
<tr>
<td>PV</td>
<td>BP</td>
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Dr. Bystryn's views on survey results

Dr. Jean-Claude Bystryn reviewed the survey results and presents the following observations:

1. PF appears to be 1/10th as common as PV, i.e. occurs in 6% vs 92% of the respondents.

2. Both PF and PV appear to be much more common in females than in males, accounting for 66-75% of the respondents. However, the possibility that females are more likely than males to respond to questionnaires cannot be excluded.

3. PV appears to be more common in Jews than in other races. This does not appear to be a result of Jews responding to questions more often, since the incidence of PF in Jews does not appear to differ significantly from that of other Caucasians.

4. Dermatologists are much more capable of making the diagnosis of PV/PF than other specialists, including GPs.

5. Pemphigus appears to occur somewhat earlier in females than in males, and to last longer.

6. Biopsies do not invariably provide a correct diagnosis. In fact, they are wrong at least once in about 1/5 of patients, and therefore cannot be relied upon entirely to reach a diagnosis. This goes along with the current recommendation that the diagnosis of PV/PF be based on the clinical appearance of the eruption, the biopsy, and the result of immuno-fluorescence studies.

Jean-Claude Bystryn, MD
Professor of Dermatology
Director, Melanoma Program
Kaplan Comprehensive Cancer Center
NYU School of Medicine
Member, NPF Medical Advisory Board
5. Who correctly diagnosed your disease? Dermatologists correctly diagnosed pemphigus in 41% of the patients responding. Dentists and oral pathologists were credited by nearly 18% of patients, while only 2.5% of patients credited general practitioners with a correct diagnosis.

The chart below reflects US patients only. Outside the US eight of the 33 patients were diagnosed by dentists, one by "Other" and the remaining 24 were diagnosed by dermatologists.

<table>
<thead>
<tr>
<th>Percentage of patients diagnosed:</th>
<th>GP</th>
<th>PV</th>
<th>PF</th>
<th>BP</th>
<th>CP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td>2%</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Derm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>59%</td>
<td></td>
<td></td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>48%</td>
<td>8%</td>
<td></td>
<td>2%</td>
<td></td>
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<tr>
<td>Dent/O.P.</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Male</td>
<td>19%</td>
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</tr>
<tr>
<td>Female</td>
<td>25%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*one patient each

6. Who misdiagnosed your disease and for how long? The numbers for BP and CP for US and NON US patients were too small to report. NON US averages are comparable to US figures below.

<table>
<thead>
<tr>
<th>US</th>
<th>PV</th>
<th>PF</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practitioner</td>
<td>Male</td>
<td>42%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>38%</td>
</tr>
<tr>
<td>Dermatologist</td>
<td>Male</td>
<td>25%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13%</td>
</tr>
<tr>
<td>Dent/Oral Pathologist</td>
<td>Male</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>19%</td>
</tr>
<tr>
<td>Other</td>
<td>Male</td>
<td>16%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>20%</td>
</tr>
<tr>
<td>Not misdiagnosed</td>
<td>Male</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>22%</td>
</tr>
</tbody>
</table>

7. Did you have an incorrect biopsy? This question should have been asked differently. Instead of asking just "Did you have an incorrect biopsy," we should have asked if the patient had a biopsy at all, and if so, was it correct? Many patients have several biopsies some may not be definitive but that is different than being wrong. In any event, 21% of men and 19% of women reported having an incorrect biopsy.

8. How long before your disease was controlled (no new lesions). If our survey is correct, men seem to get control slightly faster than women, and those outside the US do a bit better than those in the States. On the whole however, it appears that pemphigus is usually controlled between 10 months and one year. The number in parentheses is the number of patients responding to the question.

<table>
<thead>
<tr>
<th>US</th>
<th>NON-US</th>
</tr>
</thead>
<tbody>
<tr>
<td>PV M(29)</td>
<td>10.1 mo (8) 9.9mo</td>
</tr>
<tr>
<td></td>
<td>F(51) 14.1 mo* (16)10.3mo</td>
</tr>
</tbody>
</table>

*Still no control* reported by 11 females, several of whom have just begun treatment.

<table>
<thead>
<tr>
<th>US</th>
<th>NON-US</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF M(1)</td>
<td>12.0 mo (1) 3.0 mo</td>
</tr>
<tr>
<td></td>
<td>F (6) 11.2 mo</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>US</th>
<th>NON-US</th>
</tr>
</thead>
<tbody>
<tr>
<td>BP M(2)</td>
<td>4.5 mo None</td>
</tr>
<tr>
<td></td>
<td>F (1) 2.0 mo*</td>
</tr>
</tbody>
</table>

*Three females "still not controlled."

<table>
<thead>
<tr>
<th>US</th>
<th>NON-US</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP M(1)</td>
<td>19.0 mo (2) 1.5 mo</td>
</tr>
<tr>
<td></td>
<td>F (2) 0.5 mo</td>
</tr>
</tbody>
</table>
## Side Effects of Prednisone

<table>
<thead>
<tr>
<th>Condition</th>
<th>0%</th>
<th>50%</th>
<th>100%</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight gain</td>
<td>M 56</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muscle weakness</td>
<td>M 66</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muscle loss</td>
<td>M 44</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>M 25</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vertebral compression fracture</td>
<td>M 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stomach distress (ulcer, et al.)</td>
<td>M 43</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impaired wound healing</td>
<td>M 40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Varicose veins</td>
<td>M 44</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased sweating</td>
<td>M 44</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suppressed reaction to skin tests</td>
<td>M 48</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurological difficulties</td>
<td>M 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cushingoid syndrome (moon face)</td>
<td>M 48</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>M 50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>M 46</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thin hair</td>
<td>M 42</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Menstrual irregularities</td>
<td>M 41</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impotence</td>
<td>M 48</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased body hair</td>
<td>M 49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood swings</td>
<td>M 56</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced ability to concentrate</td>
<td>M 40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>M 46</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>M 47</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>The range was from a few pounds to over 150 with men averaging 15-20 and women 20-25.</td>
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</tr>
<tr>
<td>Difficult to quantify, but very common, and reported at a different rate than fatigue itself.</td>
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<tr>
<td>This points to the importance of exercise and proper diet when living with pemphigus.</td>
<td></td>
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<tr>
<td>One third reported this serious side effect, and no doubt others are affected to a lesser degree.</td>
<td></td>
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<tr>
<td>Two men and five women reported fractures of the backbone, very rare but very serious.</td>
<td></td>
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<tr>
<td>What is it about women that Prednisone affects their stomach three times as often as men?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Even minor cuts and bruises take longer to heal, and infection is a greater danger.</td>
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<tr>
<td>Do women notice varicose veins more than men, or are women 50% more likely to suffer them?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Again, women report this side effect twice as often as men, but is the reality this dramatic?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>This might be mitigated by the number of people who have skin tests.</td>
<td></td>
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</tr>
<tr>
<td>This includes such serious symptoms as convulsions, so it is comforting the rates are so low.</td>
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<tr>
<td>We are surprised this is only listed by 50-60% of respondents. We would have guessed higher.</td>
<td></td>
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</tr>
<tr>
<td>Half of Prednisone users report depression. This is significant, dangerous and treatable.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>The rate of diabetes in the United States is 5.9%, half the rate seen in Prednisone users.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>As most pemphigus patients are older, this might be mitigated by age.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prednisone and Methotrexate are to blame.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>This usually ends when Prednisone is stopped.</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Do females notice this more often? Is this complicated by menopause and other factors?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than half of all patients are troubled by mood swings while on Prednisone.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>This, combined with impaired judgement, can be serious as it affects the ability to work, drive.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slightly more women report fatigue, but it is very common with pemphigus patients.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A wide range including aseptic necrosis, fungal pneumonia and headaches.</td>
<td></td>
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</tr>
</tbody>
</table>
By Erica B. Byrne

My journey began two years ago, when I was diagnosed with pemphigus vulgaris. I tried many different medications, none of which gave me sustained improvement or remission. I am only 27 years old and I plan to have children, so I ruled out using daily oral cyclophosphamide (Cytoxan) because of the possible side effect of infertility.

In November 1998 my doctor, Grant Anhalt, told me he was trying to get approval for an experimental bone marrow ablation (chemotherapy) for pemphigus. He assured me that the high dose of Cytoxan used in this procedure is not known to cause infertility. After many months, the procedure was approved by the Internal Review Board at Johns Hopkins Hospital. I opted for this route.

I met Dr. Robert Brodsky, the oncologist in charge of my treatment, who answered my hundreds of questions. I had to have a complete physical examination, as well as extensive blood work, tests on my heart, lungs, and other functions. When I "passed" all of these tests, I was scheduled to have a Hickman Catheter (central line) placed. This enabled me to receive medications and give blood without being stuck repeatedly. For some reason I was most scared about this procedure, but it was not as bad as I anticipated. Although it was uncomfortable, it was painful only for about two days, at the site of the line. I then went to the IPOP (Inpatient/Outpatient Clinic) which is located on the Oncology Unit.

The following day, I was admitted to the Oncology Unit of the hospital. After making myself comfortable in the hospital room, I was "hooked up" to what would be my friend and shadow for many days. All of the medication hangs from a pole with wheels, which escorted me everywhere while I was in the hospital. I soon got used to pulling it along! After about two hours of hydration through the Hickman catheter, I received my first dose of cytoxan over a period of two hours. This occurred every day for a total of four days. I also received other medication to help reduce the nausea, and later I received antibiotics. On the third day I also received two units of red blood cells, due to a drop in my count. Unfortunately, I also developed a fever. Since it was uncertain as to why I had a fever, many precautions were taken, including a chest x-ray. Luckily, nothing was found.

I have to say that I remember and was awake for most of the time that I was in the hospital, but my family tells me otherwise. My husband, Tyson, my parents and friends were with me in the hospital for a large percentage of the time. I cannot begin to describe how wonderful or helpful they were, and still are.

Once I was discharged (on day five) from the inpatient unit, I returned to the IPOP daily for almost three weeks to receive medication and to give blood. Let me try to describe the daily routine. Upon arrival, my assigned nurse would check my weight, temperature and blood pressure. She would then take a blood sample to send to the lab to check my blood counts. Next I would get hooked up to my rolling friend, while receiving antibiotics (for the first 7 days), and on the tenth day of treatment I began to receive Growth Factor, which essentially jump-starts the white blood cells. All of this took at least several hours.

Sometime during my wait, the nurse brought the blood work results to me on a small slip of paper. It contained three numbers: platelet count, white blood count, and hematocrit (red blood cell count). I watched each day, as the numbers dropped lower and lower (as planned). When the platelet count dropped below 10,000 ("normal" is usually 300,000 or more), I received a platelet transfusion through the Hickman line. The white blood cells went as low as 11 ("normal" is 15,000 or higher). This was considered to be zero, which was the goal. At this time I had no immune system, and wore a mask everywhere except in my house. I also limited the people with whom I had contact, due to my susceptibility to infection. So, for about three weeks, the only places I went were my house and the IPOP clinic at Hopkins. While I was home, I took my temperature several times each day, to be sure I did not have a fever. This is fairly common, due to having almost no immune system, but I was lucky. No fever meant no readmission to the hospital. After several long weeks, you can imagine how happy I was to finally get permission to go "in public."

Ten days after I started the treatment, my hair started to fall out, in clumps, as promised. At first it did not bother me too much, but it was ALL out by the end of the eleventh day. I could not believe how quickly my formerly thick hair fell out. When I only had a few wisps left, and thought that I looked very sick, Tyson shaved the rest of me. For this was the first time I cried during my treatment process. I could barely look in the mirror, and quickly tied a bandanna around my head. After several days, I got used to my new look, and to wearing hats when I went out of the house. (I also bought two wigs in advance.)

One day at IPOP I looked at the small slip of paper and was amazed to see that the blood counts were rising again. I was right on track. Once they started rising, they rose to the desired level in only a matter of a few days. With a quick yank, the central line was removed, and I was discharged from the IPOP. Believe it or not, it was hard to leave. The nurses and doctors who took care of me were the most wonderful, caring, friendly, helpful, professional group of people I have ever met. After celebrating my discharge with a lunch out, I went home to rest, as was so often the case.

I am pleased to report that my blood work has looked very good so far. And, almost more importantly, most of the lesions have cleared up! I am down to 200 of Prednisone, which is the lowest I have been since I was diagnosed. The only other medication I am taking is an antibiotic which I will take for six months. I recently ate pizza for the first time in recent memory. I also returned to work the last week of August. Other than being more easily tired, I feel great. My hair is even starting to grow again. (It is too bad that society places such a high value on hair styles, because I am getting used to having a cooler head, and not having to wash and dry my hair every day. I sure do get ready quickly now!)

Although this process is not over, I know I am well on my way. My husband has been by my side through the whole process, and has accompanied me to most of my medical appointments since the beginning. Somehow he puts up with the Prednisone mood swings, and everything else.

Although it probably saved my life, I will only be too happy to get off the Prednisone. If the treatment was as successful as we hope, I will be able to taper off Prednisone completely, and remain PV-free!
NPF Insurance Questionnaire:

The response to NPF questionnaires has been impressive. We are delighted that our members contribute so freely of their time and experience. We urge everyone to continue to cooperate with our efforts to study pemphigus and the patients who have it.

There are several projects we are working on which require a survey of pemphigus patients. We are asking that everyone with pemphigus answer the following questions to the best of their ability and return this form before December 31, 1999.

Your information will remain confidential, only the general results of the survey will be published. Your cooperation is important and appreciated.

Janet D. Segall
NPF Executive Director

1. Did you have insurance when you first were diagnosed?
   - No
   - Yes (check all that apply)
     - Private Insurance
     - Medicare with private insurance
     - Medicare alone.
     - Medicaid or MediCal

2. Do you have health insurance now?
   - No
   - Yes (check all that apply)
     - Private Insurance
     - Medicare with private insurance
     - Medicare alone.
     - Medicaid or MediCal

3. Have you lost your insurance since you were diagnosed with pemphigus?
   - No
   - Yes.

4. Have you applied for disability?
   - No
   - Yes. If yes, what kind of disability have you applied for?
     - Workman’s Compensation
     - Social Security disability

5. If you have do not have insurance, how are you paying for your medical care?
   - I pay for my health care
   - Others pay for me (family, etc.)
   - I use the county hospital
   - Other: please state:____________

6. Is your doctor familiar with the current treatments for pemphigus?
   - Yes
   - No. If no, are you allowed to see a specialist?
     - Yes, I can see a specialist
     - No, but a specialist is consulted
     - No, I cannot see a specialist

7. Have you had to challenged your insurance company to see a specialist?
   - Yes
   - No

8. Does your health care provider cover drugs?
   - Yes
   - No

9. Have you had trouble getting your health care provider to approve certain procedures?
   - No
   - Yes. If yes, which procedures?
     - Blood tests
     - Bone scans
     - Surgery
     - Other: please state:____________

10. Did they finally approved the procedure you needed?
    - No
    - Yes. If yes, how long did it take?
      ______ months

11. Have you had trouble getting your HMO to approve your medications?
    - No
    - Yes. If so, which ones?
      __________________________
      __________________________
      __________________________

12. Did they finally approved the medications you needed?
    - No
    - Yes. If yes, how long did it take?
      ______ months
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828 San Pablo Avenue
Albany, CA 94706

The National Pemphigus Foundation
P.O. Box 9606
Berkeley, CA 94709-0606

Q21199
The Anhalt tape

A video lecture by Dr. Grant Anhalt of Johns Hopkins on current views into 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.

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The National Pemphigus Foundation

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P.O. Box 9606, Berkeley, CA 94709-0606.

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☐ I would like to donate an additional $_______ to further the work of the NPF.

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

Visa or Master Card:______________________________
Expiration date: MO: ___ YR: ___.

Name:______________________________________________
Address:______________________________________________________________
City:_________________________ State/Country:_________________________ Postal code:_____________________
Telephone:_________________________ Date:_________________________
Heart2Heart
If you need to talk to someone about pemphigus, contact one of our volunteers.

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H: 334-347-0919

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Senators Lott and Nickles would retool their bill, based on the outcomes of these amendments. These amendments included improvements to provisions of the bill dealing with access to specialty care, point-of-service plans and a prohibition of physician gag rules. Senate Republican Leaders, however, did an excellent job keeping their troops on message and in line. The Senate substitute was passed without any Republican defections.

On the other side of Capitol Hill, House Republican Leaders were faced with a much more serious problem. Republican House members had not merely “defected” to the enemy camp, but were leading the charge for health care reform. In 1998, Congressman Charlie Norwood, a dentist from Georgia, has become one of the most active and passionate members of the House on this issue. In the 105th Congress, Congressman Norwood first introduced his managed care legislation.

In the current session, Congressman Norwood has once again emerged as a leader in the health reform debate. Spurned by his leadership, Mr. Norwood joined forces with Congressman John Dingell. Together, Norwood and Dingell crafted a bipartisan measure that provided an ambitious list of reforms to both ERISA and individual health plans. The most controversial provision in the bill is the title that permits individuals to sue their ERISA insurance plans. Under current federal law, ERISA preempts state-based liability remedies that permit individuals to sue their health plans for delay or denial of benefits. The bills also provides improved internal and external appeals processes, compels plans to permit enrollees to participate in approved clinical trials, strengthens plan point-of-service and access to specialty care services, and prohibits physician gag rules.

As momentum for managed care reform started to build, House Leaders worked hard to avoid a vote on the floor, but were met with countermeasures at every turn. Successful efforts to block committee consideration of the bill were met by strong countermeasures to discharge the legislation from the committees of jurisdiction and bring it straight to the floor.

As the number of signatures on the discharge petition grew, House Leaders became increasingly concerned that they had lost control of the issue - they were right to be concerned. As momentum for Norwood/Dingell, now known as the Dingwood bill, grew, the House Leadership announced that Congressman Tom Coburn, a physician from Oklahoma, had been chosen to draft the Republican alternative to the Dingwood bill. As the weeks progressed, the reform advocacy community learned that the Coburn bill mirrored Dingwood in nearly all respects, save one - the ability of patients to sue their managed care plans.

Negotiations and redrafting continued nearly to the day that health care reform made its way to the House floor. Just prior to floor consideration, the House Education and the Workforce Committee marked up a bill, authored by Congressman John Boehner of Ohio, that became known as the conservatives’ health reform bill.

As the day approached, negotiations shifted from what the bills would look like and became more focused on how the bill would be brought to the floor. Which bill would be the base bill, Coburn or Dingwood? What about the Boehner bill? How would the access to health insurance bill being drafted by Congressman John Shadegg of Arizona fit into the mix?

Really, no one knew who would prevail until after the balloting was completed. In the end, the House Rules Committee issued a rule that provided for consideration of the Shadegg access bill first. Then, the Dingwood bill was made the base bill, with three substitutes made in order - Boehner, Coburn (now known as Coburn/Goss) and a new bill by Amo Houghton. The rule stated that if any of the substitutes passed, voting was over and the final product would be engrossed (a fancy legislative term for combined) with the access bill. The complex rule that accompanied the bill to the floor made the work of the pro-reform camp very difficult, forcing the group to rework their strategies every time a new rumor hit the circuit.

As debate ensued, opponents of managed care reform declared that the Norwood/Dingell bill was not a bipartisan measure, but a thinly disguised partisan effort by Democrats to bring us down the road to socialized medicine. Some opponents had similar unfavorable things to say about Coburn/Goss and Houghton bills.

In the end, public support for managed care reform proved too strong for the managed care lobby. The Boehner bill failed on 145-284, followed by Coburn/Goss 193-238 and Houghton 160-269. The final vote was on the underlying bill, Dingwood, and that bill did pass by a healthy margin of 275-151.

The breakdown of the bill is as follows: 68 Republicans broke ranks with their Leadership and voted for Norwood/Dingell joining 206 Democrats and one Independent. In the days following passage of the bill, pundits declared that the House and Senate would never move forward and try to conference their respective managed care bills, but the pundits have been proved wrong. The Senate has named conferees and the House is expected to do the same very shortly. Whether or not these legislators will be able to reconcile the deep differences between the two bills is uncertain, but it is a very good sign that they at least intend to try.

One final note: There is one important issue that remains outstanding - protection of private medical information. As you know, the 1996 Kennedy/Kassebaum health reform bill instructed Congress to enact medical privacy legislation prior to August 1999. The legislation further stipulated that if Congress failed to meet that deadline, Secretary Donna Shalala had the power to promulgate medical privacy regulations.

Well, the deadline has passed. No effort was made to include privacy protections in any of the managed care bills debated on the House and Senate floor. Independent privacy bills never past the starting gate, complicated by debates over abortion, parental rights and other issues. The Administration has announced that it will indeed issue medical privacy regulations, but insists that it will abandon that effort should Congress pass such legislation.
New drug reduces chance of spinal fractures 41%

After three years of testing on 450 older women, the drug Risedronate sodium (Actonel) has been shown to reduce the risk of spinal fractures by 41% over a placebo according to a report in the October 13, 1999 issue of the Journal of the American Medical Association (JAMA).

Dr. Steven Harris of the University of California at San Francisco studied nearly 2,500 women during the study. The patients were all past menopause, under 85 years and had suffered at least one spinal fracture due to osteoporosis.

Harris said that the treatment was successful even in the first year and when there already was evidence of fractures.

Actonel is already being used in the United States against Paget’s disease which produces skeletal weakness.

Unlike Fosamax, which has been shown to reduce fractures up to 50%, Actonel was seen to prevent first fractures from occurring.

Actonel is manufactured by Procter and Gamble in Ohio and Hoechst Marion Roussel in Germany. Approval for the new application of Actonel is expected as early as next January.

According to the NPF International Questionnaire results (starting on page six), one third of all patients using Prednisone will develop osteoporosis.

Tentative plans for a conference in October

The National Pemphigus Foundation has announced tentative plans for a third annual conference in October 2000. The conference will be in San Francisco.

“Since the conference in New York, we have getting feedback that members would like a conference on the West Coast,” said Executive Director, Janet Segall. “We are looking for ways to make that happen.”

Following the conference in New York it was announced that a conference would not be held in the year 2000. The NPF has held it’s conference in conjunction with the American Academy of Dermatology convention to make it convenient for doctors attending our conference.

“The AAD convention is in Memphis, Tennessee next year. Since we don’t have a chapter near there, setting up a conference would have been difficult and expensive,” said Segall. It will be much easier to set up a meeting in San Francisco since Segall and the NPF office are just across the Bay Bridge in Albany, California.

The San Francisco conference is expected to have a format similar to the meeting in New York. At this time, only Dr. Grant Anhalt of Johns Hopkins is tentatively scheduled to attend. Other speakers are being considered. A decision has not been made on the length of the conference this time. No other details have been released.

“San Francisco has some of its best weather in September and October, and there is never a shortage of world class restaurants,” said Segall.

If we raise more, we can do more

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yourselves while helping the Foundation. Ask the store you shop at often to donate an item for auction. If you are involved with a local support group, encourage the group to get together and plan a fund-raising event. Often local bands or restaurants will give of their time or facility for a good cause.

Unfortunately, we are competing with many other organizations for the same money. Because other foundations have been around much longer than we have, and exist on budgets 10 times ours, we are in a fight to stay afloat. We need to recognize, however, how far we have come on the little we have.

The efforts dedicated to keeping this Foundation going are intense. I have the best people working with me to make sure that it does. We are important. We function to help. Support us!!

Janet Segall
Executive Director

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