International Pemphigus Meeting Held in Switzerland

Nestled in the pristine Swiss Alps, the Hotel Allegro in the city of Berne, Switzerland was the location for an international meeting discussing all aspects of pemphigus. The meeting consisted of 3 days of intense scientific discussions. The meeting was co-sponsored by the IPPF and many members of the IPPF Medical Advisory Board were present. Included were Dr. Jean-Claude Bystryn, NYU Dermatology; Dr. Sergei Grando, UC Irvine; Drs. John Stanley and Victoria Werth, UPenn; Prof. Michael Hertl, Phillips Univ., Germany; Prof. Marcel Jonkman, Univ. of Groningen, Netherlands; Prof. Pascal Joly, Rouen Univ., France; Dr. Masa Amagai, Keio Univ., Japan; and Dr. Grant Anhalt, Johns Hopkins University. Ms. Janet Segall was there representing the patient’s perspective and the IPPF.

Professor Eliane Muller, President of the meeting’s Organizing Committee, and a member of Molecular Dermatology, Institute Animal Pathology, Vetsuisse Faculty, University of Berne, Switzerland, welcomed the speakers and participants. Janet spoke to the group about the importance of the IPPF and patient groups in general, highlighting that with a rare disease, it is often difficult for patients to find cohesive care and Foundations can be the glue for many.

Janet thanked all of the doctors for being there and for all the care they give to patients, to Janet herself, and to the IPPF.

With the meeting officially open, the presentations got down to the intricacies of cell development, cell adhesion, and cell signaling. At the end of the day, the groups broke up into workshops with more technical discussions or workshops about treatments. Although all

Continued on page 5...
From the Top

W

hat happened to the lazy days of summer? After slicing and drying almost 300 pounds of tomatoes from my garden, it is a happy frenzy when I get to the IPPF office – which is, at least, air conditioned. Will has been lifting the heavy weight of building an automated system that delivers our direct patient support in a much more streamlined way. Now you can call your Peer Health Coach directly, no matter where they are. In addition, we have added mechanisms to ensure timely follow-up with requests that come from the website, Forums, phones, or emails, and even better, to request, from those helped, feedback on our services and suggestions for improvements.

Part of this technology improvement has gone to strengthen our data registry. We now have, in just slightly over one year, 171 (as I write this) people surveyed through our Health Management Program. This means that we have what is close to statistically significant data on the natural course of P/P disease and reliable evidence of treatment outcomes and side-effects. Finally we can provide that data (all de-identified and anonymous) to doctors to develop “Best Practices” standards for treatments. This allows doctors not familiar with treating P/P to have some confidence in the course of care they offer and, in the anticipated success of different options. Most importantly, having large scale information on your illness experience, treatments, outcomes and complications will allow the IPPF to more effectively pursue policy and discovery opportunities that improve treatments, outcomes and your quality of life. Watch for more news on the registry environment and your vital participation...having information from a large number of patients will optimize the accuracy of our insights and our effectiveness in illness advocacy. In addition, we can give data to researchers to identify trends and potential mechanisms to manage or cure the influence of those rogue antibodies.

We still need your help. Having 500 patients surveyed provides a much richer set of data points to enhance confidence in the choices that doctors and researchers make about fruitful areas of pursuit (we have over 3,500 patients that CURRENTLY use our services). We need your data. To this end, Will, again is working his wizardry to put our survey’s online so that even people who do not want or need the added comfort of a personal “Peer Health Coach” can still contribute to this wealth of knowledge about these wildly misunderstood diseases. Please, call us or go to the website and indicate that you want to participate in the “HMP” Registry data collection to help advance a cure. You can request information at www.pemphigus.org/hmp.

For those of you who truly appreciate the opportunity to connect to a Peer Health Coach, we have expanded our program and now have numerous coaches, located across the country, including both men and women coaches and

Continued on page 3...
The following people made donations (May, June, and July) that will be doubled as part of the Double the Difference campaign. You can donate at any time.

Fatima Campos
Amy Busch
Dawn Burson
Cathy Burns
Sidney Blum
Cynthia Blum
Karen Berkey
Eli Ben-Dor
Marie Bell
Marla Beeson
Ann Barberio
Farideh Assadi
Lori Aronovitz
Lydia Altman
Cynthia Alexander
Joann Albrecht

We also especially need you to support the IPPF in 2009. The conference of P/P luminary medical professionals to define the “Best Practices” in treating this disease – which will help, literally hundreds of P/P next year alone – has a budget of nearly $25,000. The money will be spent to gather data, evaluate completed studies and to produce and publish a scholarly paper as well as provide the results to ALL of the practicing “main street” medical-dermatologists in the US. Fortunately, the IPPF has been honored in 2009 with a Matching Donation Campaign (see details on page 11) which allows every dollar donated this year to do twice the work and make twice the progress. We know this is a tough economy for everyone, but we are anxious to continue our momentum in making a real difference in the course of this disease; Please give what you can, or give again if you can.

After the registry contains robust numbers of patient data we have plans to implement a tissue collection bank to augment the data report with actual samples of blood, tissues, etc – as the foundation for medical trials -- more on that next time.

PS: Make plans now to join us in Philadelphia, PA April 30-May 2 for the 2010 Annual Meeting. And let us know if you have any connections in Philly that could help make it a great(er) meeting!!
Developing Products for Rare Diseases & Conditions

The Office of Orphan Products Development (OOPD) dedicates its mission to promoting the development of products that demonstrate promise for the diagnosis and/or treatment of rare diseases or conditions. In fulfilling that task, OOPD interacts with the medical and research communities, professional organizations, academia, governmental agencies, and the pharmaceutical industry, as well as rare disease groups.

Prior to passage of historic legislation, private industry had little incentive to invest money in the development of treatments for small patient populations, because the drugs were expected to be unprofitable. For these drugs, intended for diseases or conditions affecting 200,000 or fewer persons in the United States, there is no reasonable expectation that costs of research and development can be recovered by sales of the drug in the United States, leaving no one to pursue development for rare disorders.

The Orphan Drug Act (ODA) of January 1983, passed in the United States with lobbying from the National Organization for Rare Disorders, (of which the IPPF is a member), is meant to encourage pharmaceutical companies to develop drugs for diseases that have a small marketscope. Since the market for any drug with such a limited application scope would, by definition, be small and thus largely unprofitable, government intervention is often required to motivate a manufacturer to address the need for an orphan drug. Critics of free market enterprise often cite this as a failure of free markets. Free market advocates often respond that without government-mandated minimum safety and efficacy requirements, drug development costs would be considerably lower. Under the law, companies that develop such an "orphan" drug (a drug for a disorder affecting fewer than 200,000 people in the United States) may sell it without competition for seven years.

The law provides three incentives:

1. 7-year exclusive marketing rights, (which limits competition by preventing other companies from marketing the same version of the drug),
2. a tax credit of 50 percent of the cost of conducting human clinical trials, and
3. Federal research grants for clinical testing of new therapies to treat and/or diagnose rare diseases.

In 1997, Congress created an additional incentive when it granted companies developing orphan products an exemption from the usual drug application fees charged by the Food and Drug Administration (FDA) -- these fees will total almost $500,000. Companies also may be eligible for faster review of their applications for marketing approval if their products treat a life-threatening illness. Many orphan drugs treat a serious or life-threatening disease.

Orphan drugs generally follow the same regulatory development path as any other pharmaceutical product, in which testing focuses on stability, safety and efficacy. However, some statistical burdens are lessened in an effort to maintain development momentum. For example, orphan drug regulations may not be possible to test 1,000 patients in a phase III clinical trial, (as is required for other drugs) as fewer than that number may be afflicted with the disease in question.

In the USA, from January 1983 to June 2004, a total of 1,129 different orphan drug designations have been granted by the OOPD and 249 orphan drugs have received marketing authorization. In contrast, the decade prior to 1983 saw fewer than ten such products come to market. Nevertheless, some critics have questioned allowing some pharmaceutical companies to make a large profit off of drugs that have a small market but still sell for a high price.

A new question has arisen now over the drugs that we now call "biologics". A biologic is a medicinal product that is made from a living organism or its products -- including blood and blood components, allergens, somatic cells, gene therapy, tissues, and recombinant therapeutic proteins created by biological processes (as opposed to chemically). Biological drugs include antibodies, interleukins, and vaccines. Biologics can be composed of sugars, proteins, or nucleic acids or complex combinations of these substances, or may be living entities such as cells and tissues. Biologics are isolated from a variety of natural sources - human, animal, or microorganism - and may be produced by biotechnology methods.

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current treatments were discussed, the main topic of discussion was centered around the use of rituximab. Many of the participants felt that rituximab may be the most effective drug so far for treating pemphigus, and at some point in the future, could possibly be the first line of defense in our fight, however, concern was expressed about its side effects. IVIg was also considered and discussed at length as a very viable treatment as well.

On a personal note, the day concluded with a wonderful dinner where the doctors and the IPPF surprised Janet with an award, a plaque, and a letter that Will had secretly gathered from Dr. Steve Katz, Director of the National Institute of Arthritis, Muscular and Skin Diseases (NIAMS). Janet says, "I was humbled and honored, and I thank everyone for their respect and support."

Day 2 and 3 continued on with discussion about stem cells, epidermal renewal, mechanisms of acantholysis (loss of cell cohesion), how the immune system responds in pemphigus, and the continuation of targeted therapies for our diseases. After 3 grueling days of discussions, Prof. Muller rented a boat in the nearby town of Murten for a dinner cruise. Everyone who attended let their "hair down," danced, and sang karaoke as they cruised around the Lake of Murten. A good time was had by all.

Janet reports that, "It was a gift and an honor to be included alongside such distinguished physicians and researchers in the field. Although some of the science was over my head, everyone treated me and my opinions as valuable contributions to the conversation. I am awed to have been in such esteem company. If anyone is going to find the answers for us, it will be these special, dedicated people who have decided that we are worth it."

Special IPPF thanks go to Janet for always representing the needs of the patients so ably!
Coordination of Care

With Pemphigus and Pemphigoid (P/P) the “captain of the ship” regarding your care is usually a Dermatologist. After a diagnosis is made, then perhaps there is an initial telephone call or letter sharing information with your primary care physician, but then what happens? Do the various doctors involved continue to communicate regularly? Do they touch base if there is a flare or new treatment being used? Do they all get results of medical tests and blood work? Or, as so often has been observed, is everyone flying solo?

Sometimes the “system” encourages or discourages the dissemination of information. For example, psychologists are generally required by insurance companies to send an initial letter to a patient’s PCP and sometimes others involved in the person’s care. The letter makes clear that coordination of care is important in the treatment of the patient. At times that letter is the only communication, but more often there are shared phone calls and faxes regarding essential information.

Under other circumstances care is coordinated only if a problem is detected. For example, women are used to going for a gynecological exam yearly and for mammograms after a certain age. If no problems are detected the exam or test results are likely not shared, unless the patient does so. If a problem is noted, then the wheels go into motion for sharing findings, which are often life-saving. This is true for colonoscopies and other procedures as well.

When the diagnosis is common, like heart disease or cancer, there is usually a protocol in place, with specialists working together to ensure coordination of care. However, with a disease like P/P, do the doctors, dentists, dermatologists or others involved in specific areas actually communicate? How can the patient or caregiver ensure that information is being shared, or even being recorded? How can the patient or caregiver help?

One of the ways a patient can try to encourage communication is to be clear in asking for everyone to be updated. When getting medical tests or lab work/blood work, request that all of your doctors receive a fax or copy of the results. Provide each of your doctors with a sheet naming your other doctors and sharing their fax and phone numbers. Even if the recipients do not see it immediately, which they may not, the record will be in your chart – which will continue to get thicker. Furthermore, if you are made aware of a test result which is NOT within normal limits you may want to contact your other doctor’s offices to make sure they are notified of the new finding. This will empower you to be your own best advocate.

Some people change doctors and dentists if they believe that their concerns are not taken seriously, many have changed because of the belief that they were not being treated as a whole person any more. It will probably be important to remind your doctors that you are a whole person, and that with this one uncommon diagnosis you also have, other issues that may be either separate or interwoven. Often symptoms (such as dry mouth or joint pain/fatigue) are blamed on medications prescribed and sometimes these are bona fide symptoms.

All of your doctors (and dentists) can be given a complete list of medications and doses for all variety of conditions you may be treating through other professionals. Keep a copy and change it as necessary to keep it up to date. Also, carry a copy around with you. If you are part of Medic Alert, they will keep the list up to date for you if you just call in any changes, don’t forget to let them know. It is good to keep a record of allergies and allergic reactions to medications, also. This just may save your life.

Lastly, please remember that you know your body and how you feel better than anyone else even though you do not have a medical degree. You may note that certain things prescribed by one doctor seem not to fit with what you’ve heard from another. Pay attention to the details of what treatments seem to work or feel better than others, listen well, ask questions, remind your busy doctor to review additions to your chart and tell him or her of your visits to other doctors and their changes in advice. In closing, please remember to be your own best advocate and to find answers to your questions. You may not be totally in charge, but at least you will not be a passenger in your health care and life.

(I would also like to thank the writers of the television show House for having Dr Gregory House peel an onion in a patient’s room at the end of that one episode last year! - Terry -)

Dr. Terry Wolinsky-McDonald is a licensed clinical psychologist in the Pittsburgh, PA area. She is a member of the IPPF Board of Directors and frequent contributor to the Quarterly. Her articles focus on the psychological aspects of living with P/P in patients, caregivers, and family members.
and other technologies.

Unlike the more common traditional "small-molecule" drugs, biologics generally exhibit high molecular complexity, and may be quite sensitive to manufacturing process changes. Original patent-owner manufacturers have a molecular clone and original cell bank, and specific fermentation and purification processes. Finally, nearly undetectable differences from individuals in impurities and/or breakdown products are known to have serious health implications. This has created a concern that generic versions of biologics might perform differently than the original branded version of the drug.

So, unlike most drugs, generic versions of biologics are not authorized in the US or the European Union under the same benefits applied to other drugs for orphan illnesses. This could wreak havoc as biologics are particularly expensive to develop but are relevant to orphan diseases such as P/P -- treatments like IVIg, etanercept/Enbrel or infliximab/Remicade.

Because they are hard to copy exactly, biologics have not been subject to the generic competition that eventually knocks down the price of drugs like Lipitor and Prozac. Congress, as a cost-cutting piece of the overall health care effort, is preparing legislation to enable the US FDA to approve copycat versions of biologic drugs. That could save consumers, insurers and the government billions of dollars in the coming years. The trick is to allow competition without undermining the financial incentives the pharmaceutical industry needs to undertake the risky job of developing the next drugs for cancer and other diseases.

Pharmaceutical trade groups say they require a 12-14 year exclusivity period in order to recoup their investments, but consumer groups, insurers, employers and generic drug companies say anything more than five years would eviscerate any potential savings from the new competition. So far, the biotechnology industry appears to be winning. The United State Senate’s health committee, for example, has agreed to 12 years of exclusivity. In the House, a bill that provides at least 12 years of exclusivity has many more co-sponsors than one that would provide five years.

The Obama administration has said that seven years would be a ‘generous compromise!’ But an exclusivity period could affect biologics that have already been on the market for over a decade. As for cost savings, the Congressional Budget Office has estimated that generic biologics might save the government only about $10 billion in the next 10 years, but the real savings might come more than 10 years out, as new biologic drugs appeared and as biologics represented an increasingly greater part of overall spending on drugs.

Keep your eye on this evolving dilemma.
FAITH
VISION
SACRIFICE

HONORING IPPF FOUNDER
JANET D. SEGALL
Janet said, "I thought I would try to start the Foundation. Unfortunately, I was not prepared for the enormity of the task, and found it all quite overwhelming; so I gave it up; though I continued to look for others and gather information." This was taken from The PV Foundation News, Volume 1, Issue 1, March 1995 - all five pages.

Nearly seven years before starting what would become the IPPF, its founder, Janet Segall, walked away because the task overwhelmed her. These diseases can do that to a person - overwhelm them. But she did find a way. She woke up one morning to say, "I'm going to do it."

Where would patients be today had Janet not found the courage to take pemphigus on full force? But Janet was compelled to make a difference - and what a difference it was!

On July 31, 1994, the PV Foundation’s Board of Directors gathered in San Francisco. There, five people met to lay the foundation for this Foundation. Their first official meeting was in February 1995 after becoming a 501(c)(3) in October 1994.

There will always be adversity to face regardless of the reason; change is inevitable in life and unless a person can accept and overcome it, they will be consumed by it. Janet continues her efforts to champion change, advocacy, patient rights, and peer support on a much broader scale.

True to her original commitment, Janet continues to counsel pemphigus and pemphigoid patients, and now she will also offer her counseling skills to those with other autoimmune diseases.

The work Janet did with the Foundation was life-saving to thousands of people around the world. Statements like, "I would be lost without Janet and the IPPF" and "Janet saved my life" are commonly heard around the offices, on the Community Forums, and in the Email Discussion Group. Luckily for the IPPF, patients continue to benefit from her knowledge and experience.

I woke up one morning and said, "I'm going to do it!"

Janet is in the early stages of a new startup venture to educate and counsel patients regardless of their disease. Janet is scheduled to take additional classes that will add to her repertoire of skills and further benefit the patients.

What started as one woman's journey for help became a unified effort of hope; a common hope... an uncommon bond. All of us honor Janet for her courage, wisdom, perserverence, and commitment to our cause: finding a cure.
A Look Back on the IPPF: Good Memories and Great Friendships

As a member of the IPPF BOD and one of Janet’s longest standing supporters, I wanted to reflect on where Janet brought us from -- and to.

Janet Segall has had many outstanding accomplishments since she started the Foundation in 1994. In fact, it could be said that it was a textbook organizational growth plan. In that first year, Janet was a single parent from San Francisco with a teenage daughter, Tina. Janet had been living with Pemphigus Vulgaris for 10 years and could not find the needed support anywhere.

With donations from family and friends, she started a non-profit 501(c)(3) organization called the National Pemphigus Vulgaris Foundation (NPF), later International Pemphigus Foundation (IPF), and most recently the International Pemphigus Pemphigoid Foundation (IPPF). She worked hard to form a Foundation Board of Directors -- which has grown to 12 members. Janet then started networking with the best dermatologists in the United States and Canada (and later the world) with the help of Dr. Grant Anhalt of Johns Hopkins University and Dr. Jean-Claude Bystryn of New York University. A Medical Advisory Board was soon formed which now has 20 members from all over the world.

Physicians and pemphigus researchers started talking to each other with her help and have developed protocols for drugs such as Imuran, IVIG and Rituxan. With Janet’s encouragement, many of our pemphigus and pemphigoid physicians referred their patients to the Foundation. Janet was an early supporter of the internet which provided a fantastic tool for patients to discover the organization and communicate with each other via an e-mail list server.

A quarterly newsletter provided vital information to patients and physicians. Patient Support Groups were started in Los Angeles, San Francisco, New York, and Toronto with Boston, Philadelphia, England, Israel and Italy soon following. The next step was an annual meeting. The Annual Patient/Doctor meetings connect patients and caregivers with the latest information. The IPPF also participates with major dermatology organizations as well as with the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), International Alliance of Patient Organizations (IAPO), and the Coalition of Skin Diseases (CSD), to name a few. Our organization has even spoken to members of the United States Congress on autoimmune diseases and health care funding.

Today we have outstanding partnerships with many major drug and healthcare companies and our partnerships with them have helped research and patient profiling. The Foundation’s budgets grew from $10,000 in its first year to a budget which now provides for an office in Sacramento, CA with an outstanding staff which serves and provides support to patients from around the world.

Most importantly, Janet has made life better, healthier and happier for countless people worldwide. As the ultimate tribute, Janet found the right physicians at a critical moment and saved MY life. To show my gratitude and offer guidance of the IPPF’s future, I serve as Secretary/Treasurer on the Board of Directors. I can think of no better way to show my appreciation to Janet and the Foundation than to donate my time to making the IPPF better each and every day.

Thank you Janet, for your unselfish gift of vision, support, and sacrifice to pemphigus and pemphigoid patients!

Lee Heins
Director, IPPF
DOUBLE the DIFFERENCE

Do you want each dollar you invest in the IPPF to make TWICE as much impact?
Do you want to AFFIRM how important progress for P/P is to you?
Do you want to make a difference for FUTURE generations?

YOU can

- Support Systematic collection of data to identify Best Practices and Effective Treatments
- Promote fast and accurate diagnosis for early, meaningful resolution
- Ensure biologic tissue sample collection
- Enable scientific research
- Support systems for patients in crisis
- Assist with insurance challenges
- Inspire new Treatment therapies

Generous members of our community have pledged to MATCH every donation dollar we collect in 2009 up to $200,000!

Things to do today:
1. Donate to the IPPF
2. Join the HMP
3. Get involved
4. Smile!

Smiley face
Over the weekend of the 26th June 2009, the PEM Friends arrived to spend time relaxing and meeting old and new friends. We stayed at The Stables, owned by Carolyn & Raymond Blain, in Ashton-under-Lyne, in the North West of England, and just eight miles from the centre of the City of Manchester.

The weather was warm and sunny. In fact so good that the PEM Friends flag on the flagpole in the Blain’s garden never even fluttered, so people who had never been before didn’t get a chance to see it!

We had good food and wine (won’t tell you how much!) and of course, good company, all ensuring the weekend was a success from the start.

On the Saturday evening the “girls” made a big effort for the Gala Dinner held in Carolyn & Raymond’s garden. It was good to see them all looking so glamorous and everyone enjoying themselves — and the men looked good too!

Many thanks go to Carolyn & Raymond for hosting this weekend and before people left for their destinations it was amazing to see everyone so happy and relaxed. A tonic indeed for the people who were in need.

Raymond and Carolyn — thanks from everyone who came to your home.

Love from John & Edith
Another really enjoyable and informative week-end was had by us all at Ashton-under-Lyne. It was so nice to meet up with lots of old friends and to meet a few new ones. It was a shame that no-one from far-away shores was able to make it this year as we like to hear how friends from abroad are coping with our condition.

We met up on Friday and were superbly cared for by Carolyn who cooked us all a lovely meal which we ate around the large table in the kitchen of The Stables. After much good food and wine and lots of shared information, the twelve of us went to our beds.

After a hearty breakfast on Saturday morning (I am pleased to say that I am now a great fan of cooking on an AGA) we met two more new friends who came to join us for the rest of the weekend.

Most of the ladies amongst us made their way to the local market where we all picked up some really good bargains. The gentlemen amongst us, having an aversion to shopping, went for a long walk along the river (although I did manage to get my husband to KEA!!)

On Saturday evening we were the guests of Carolyn and Raymond at their lovely home for a very sumptuous Gaia Dinner, where we also met up with two more of our old friends who joined us just for the evening. With Carolyn and Raymond we were then sixteen in all. The weather was glorious and we were able to sit outside on the patio and enjoy the splendid views across the countryside.

I know I speak for everyone when I say that we really appreciate Carolyn and Raymond’s hospitality and kindness in arranging these week-ends every year as it has made such a difference to every one of us all in being able to meet up with fellow “sufferers” so that we are not so alone and isolated. The new ones amongst us went home feeling much more knowledgeable about their condition.

Looking forward to next year!!!

Love from Barbara and Barry

Barry toasts the camera and another wonderful Away Weekend

Dorothy, Barbara, and Edith

Margaret, Barbara, and host Carolyn Blain
RSS stands for Really Simple Syndication. What it actually is can simplify the lives of the information-starved from the comfort of their home computer, laptop, or mobile phone.

There is a technical side to RSS and to go into great detail would probably lead me down the path my family likes to call, "Will’s World." As wonderful of a place as it is, it reads like stereo instructions with the schematics to boot. I'd have to cover XML, channel elements, version history (it is now at 2.01 in case you're wondering), and a ton of other techno-gobbly-gook.

So for simplicity’s sake, let's say that RSS is an easy way to have information sent to you where you want it on the topics you want to know about. Using Internet Explorer 8 you can add an RSS "feed" to your Favorites menu. In Vista, you can add them to a Sidebar with an RSS reader.

Why use RSS?
Rather than go to each of your favorite websites one at a time to see what's new, you can subscribe to a feed from them and scan the syndicated headlines (or photos, or podcasts, etc.). See something you like? Click it and get the rest of the story!

Think of it as your own personal assistant scanning the websites you visit and the newspapers and magazines you read and giving you a quick summary of the latest news. It is almost like your very own news ticker scrolling through your life (think CNN®, ESPN® and other news channels with the informative news bar at the bottom of the screen).

I have RSS feeds on my Microsoft Vista-based computers at home ("Chicago sports" and "Adobe products") and work (Adobe products, news, and the IPPF Forums).

You saw that right - the IPPF Forums as an RSS feed! I like to keep them on my desktop so I can keep my finger on the pulse of the Community. I know, cliché, but it really does help.

Want to give it a try?
Go to the Community Forums (community.pemphigus.org) and click on the RSS icon at the bottom of any forum page. When that window opens, you need to copy and paste that URL into your RSS reader. That's it!

What's the Catch?
You can't reply to an RSS feed. You can read the forum post, but need to log into the Forums to post your reply. However, in the bottom image you can see the word Link under the story; click it and it takes you to that posting (you may have to log in first). Unless you respond to nearly all postings, this is a great way to get your daily dose of the Forums on your phone or computer when you have time.

Prefer the newspaper look? Check out www.feedjournal.com and turn RSS feeds into a printable .pdf file!

If you have a question, drop me an email at will@pemphigus.org. Enjoy!

Here are two images of the RSS reader on my work desktop showing feeds straight from the IPPF Community website. On the left you can see what I see while I work (notice my email open next to it?). Above you can see that when I click on a feed of interest it gives me a flyout of the actual information from the Community Forums. And yes, it is a brisk 69 degrees at 9 am as I write this article. Can anyone tell me where Summer went? Alas, while that is important, it is not as important as me being able to glance at the feeds and stay up to date with the Community.
For Immediate Release

IPPF Quarterly wins two APEX 2009 Awards of Excellence!

SACRAMENTO, CA (JULY 2009) - The International Pemphigus & Pemphigoid Foundation, the global leader in pemphigus and pemphigoid patient support, has been awarded the APEX 2009 Award of Excellence in two categories, MOST IMPROVED NEWSLETTER and NEWSLETTERS - WEB & ELECTRONIC, for its Spring 2009 Quarterly newsletter and eQuarterly online version.

APEX 2009 -- the 21st Annual Awards for Publication Excellence -- is an international competition that recognizes outstanding publications from newsletters and magazines to annual reports, brochures and Web sites.

According to the APEX 2009 judges, "The awards were based on excellence in graphic design, quality of editorial content and the success of the entry in conveying the message and achieving overall communications effectiveness."

The Spring 2009 Quarterly (issue #56) was the IPPF's Special Support Issue and focused on ways members of the IPPF Community have supported research, awareness and one another. It also included information of its 2009 Annual Patient/Doctor Meeting in Los Angeles, CA, welcomed a new member of the Board of Directors, and showcased the work of the Boston Support Group at the 34th Yankee Dental Congress in Boston, MA. The issue’s cover story was from a mother and her teenage daughter who used various support networks to cope with pemphigus vulgaris, a rare, autoimmune disease of the skin and mucous membranes.

About the APEX Awards

The APEX Awards for Publication Excellence is an annual competition for writers, editors, publications staff and business and nonprofit communicators. It is sponsored by Communications Concepts, Inc., publishers of business communication reports, including Writing That Works, a subscription bimonthly for professional communicators, and special reports on topics such as writing feature articles and Web publishing.

In the Twenty-first Annual APEX Awards, awards were given in 122 communications categories, in 11 main categories including: newsletters; magazines and journals; magapapers and newspapers; annual reports; brochures, manuals and reports; electronic and video publications; Web and intranet sites; campaigns, programs and plans; writing; design and illustration; and one-of-a-kind publications.

About International Pemphigus & Pemphigoid Foundation

The IPPF is the pre-eminent global organization dedicated to improving the quality of life of all people diagnosed with, or affected by, pemphigus or pemphigoid. The IPPF provides direct access to innovative and effective support that promotes the very best health care, improves quality of life, stimulates community resources, advocates for favorable government policies, accelerates the pace of scientific discovery and is the world’s best source of information on pemphigus and pemphigoid. The IPPF is compassionate in understanding, tireless in service, and relentless in advocating. One person at a time, the IPPF makes a difference, building a community of care and hope.
2010 Patient Doctor Meeting

Friday, April 30 - Sunday, May 2
Philadelphia, Pennsylvania

Save the Date