How Patients and Patient Advocacy Groups Get New Treatments Approved

Did you know that it takes an average of $800 Million and 8 years for a drug manufacturer to complete research and development, prove safety and efficacy in multiple clinical trials? (read more at http://bit.ly/6wMxgk) More so, in the arena of drugs for small population "orphan"-illnesses, drug companies have little incentive to go down this road when they can only sell any resulting drug to a few hundred people.

Compare that to 118 million prescriptions for antidepressants and 113 million prescriptions for high blood pressure drugs, in 2005 alone!

The FDA, recognizing this disincentive to develop better treatments for orphan diseases, has developed strategies to allow, encourage, and make possible the development of drugs -- even for small populations.

Because so much of the cost of drug development happens long before a drug ever (might) be sold -- a hurdle to even getting started -- the FDA has modeled some new concessions that could allow drugs to be released earlier to needy populations. These are tied to ongoing followup through a new program called REMS (Risk Evaluation and Mitigation Strategy). Now, with well documented and consistent survey data of a drug’s impact, a manufacturer may be allowed to release a drug that has not completed traditional drug-to-market clinical trials, when circumstances like a too small population exists, which can allow people with no good treatment solutions to have access to medicines in ways

Continued on page 5...
I was in Tennessee this week, seeing the colors of the trees burn across the ridges, and feeling the fall induced opportunity to feel gratitude. As you get this, we’ll all be deep into the holidays and winter, giving us a chance to reflect on the gifts of the year.

Some things we’ve had a chance to be grateful for this past year include the vision and inspiration that Janet dedicated to the cause of helping those with a “common bond”, the courageous/relentless visioning of the future by Dave Sirois, President of your Board, whom I work with weekly on our strategic plan to make headway in awareness, research, treatment and advocacy. And, the rest of the Board each gives, above and beyond, of their own special talents.

Will, of course. He gives his all, all the time, (my favorite is, “Sure, I can do that!”) with a wealth of expertise and skill and energy to learn new things that is beyond compare. Thanks, Will, for it ALL!

And, of course, each of us is so grateful for the generosity of others who share your concerns and are moved to making a difference. The Double the Difference Donation-Match Campaign inspired over 200 NEW donors in 2009 and over 41 donors gave more this year than they did last year. Despite the bleak economic situation, your determination has taken us within $35,500 of earning the full $200,000 match -- and there’s still one month to put us over the top. Please consider the impact a donation this year could make when you receive your holiday fund-drive mailer -- and give your feedback on what you care about, it matters to all of us!

With these funds we have build an online data registry to make data collection faster, easier and more accurate (see information about our 1010 in 2010 drive on page 5); we are partnered with National Disease Research Interchange (NDRI) and the NIH to begin blood and tissue sample collection to be used for direct medical research; and we have trained and added two new Peer Health Coaches, Marc (BP, in the West) and Yvette (PV, in the East) to get more patient questions answered faster and more conveniently; finally, we will be hosting a Scientific/Medical Consensus Conference of the luminary P/P doctors worldwide and an audience of over 150 doctors, in the Fall of 2010 in Bethesda, MD in conjunction with the NIH. There, the goal is an agreed-upon, evidence-based protocol that can be shared with doctors with less expertise, to improve treatment outcomes and a discussion of promising discoveries at the cellular/immunological level. These conference should result in at least two publications advancing medical knowledge of P/P worldwide. And the IPPF 2010 Annual Meeting, of course! (see this issues center spread)

Which just leaves the over 4,000 of you we communicate with monthly by email, the over 600 who choose to subscribe to our paper newsletter, the 4,600 who read our newest news and information in real time on our News & Information site (www.pemphigus.org/news), Facebook, and Twitter, and the more than 350 new patients who personally contacted us this year. Each of you gives, in the thank-yous you share with us, in the discussions you have with your neighbors, in the awareness building projects you develop in your communities, in the outreach you do to others that are hurting, or confused, or afraid, in the courage with which you move forward. Your time, and a hand along this journey, are gifts beyond measure.

Blessings,
2010

March
5-9 American Academy of Dermatology (AAD) Annual Meeting (Miami, FL)

April-May
30-2 IPPF Annual Meeting (Philadelphia, PA, USA)

August
4-8 American Academy of Dermatology (AAD) Summer Meeting (Chicago, IL)

For more information visit www.pemphigus.org/events

Thank You to our Supporters!

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 by visiting www.pemphigus.org/donate.

Rhoda Abzug
Alwyn Cream
Esfira Annenberg
Tony Arauz
Debra Barron
Valerie Berman
Judith Bernstein
Cynthia Blum
Joan Bonner
Robert Boublitz
Margaret Breedlove
Darlene Brin
Donna Bunch
Centric Health Resources
Sandy Chamen
Aliza Cohen
Vincent Crociati
Charles Doherty
Carla Eggers
Julia Engel-Bennett
Dana Epstein
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Mei Ling Moore
Alan Livingston
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Lillie Swanson
Annie Thompson
Mindy Unger
Amy Weber
Barbara Weinstein
Laurel Wexman
Terry Wolinsky-McDonald
Wallace Wolman
Kim Yancey
Fred Youngswick

We apologize for any omissions.
Industry Years Behind on Testing Approved Drugs
Federal drug officials have long been criticized for failing to force drug makers to complete studies...

Steps to Greater Accountability in Medical Education
To remain certified, most of the nation’s 700,000 doctors are required periodically to take continuing medical...

Health Coaching via an Internet Portal for Primary Care Patients With Chronic Conditions
Patients suffering one of three chronic conditions reported improved communication with their primary...

Patients protest losing drug coverage
A group of New Mexicans is protesting changes by Presbyterian Health Plan that now deny them a drug...

Read more about the following stories online

Read all about it!
New stories added each week!

www.pemphigus.org/news
For the latest in P/P news and information

SAMPLE STORY

Will Consumers Pay Out-Of-Pocket For Online Healthcare?

If you suspect your extra-curly baby has an ear infection on a Saturday afternoon, but his doctor isn’t back in the office till Monday, a walk-in clinic-like the kind springing up in places such as retail pharmacy chains—can be a convenient place to get the ear checked. But if it’s the middle of the night, what do you do?

Starting in late 2009, consumers will be able to hook up with physicians and other clinicians online any time of day via two-way video, webcam, secure chat, or phone. An alliance between America’s Well, which provides a secure online health marketplace, and OptumHealth, a subsidiary of UnitedHealth, is setting the stage for a nationwide, 24-by-7 telemedicine service that links consumers with healthcare professionals in their states.

Over the last couple of years, a number of retailers have begun opening these walk-in clinics, including CVS, Wal-Mart and stores...

If you do not have Internet access and would like a copy of one of the stories, please contact Will at 916-922-1298 x1003 and he would be glad to send you a copy. Please provide the title of the article you would like, your name, mailing address, and phone number where we can contact you.
they never could, while still providing the FDA with all data necessary to ensure safety. Recording good quality data on the effects of drugs -- like rituximab -- being tried for P/P helps those drugs gain FDA approval if there is evidence they are effective. This opens the door to better access, more insurance coverage, and better options.

In addition to sharing data about medications and disease history on an aggregate, de-identified basis, patients support the development of new drugs by participating in clinical trials. It would be a challenge for a manufacturer to even be able to run a clinical trial in many rare diseases as the patients are far apart, not well connected and, definition, few. The more patients connect to patient advocacy groups representing rare disorders, the better chance that a drug study could be offered to more people to allow for meaningful proof of effectiveness. This is true also of tissue-bank collections. With an extensive spectrum of blood/tissue samples available for analysis, opportunities for seeing patterns that may provide answers, increase.

Most drug manufacturers of orphan drugs begin their clinical trials process by reaching out to patient organizations to help them get connected to their relevant community. Because medical information is protected, no patient/member names may be disclosed, however, information about a trial may be sent out and patients can investigate further if they are interested.

How does this relate to you?

The IPPF is launching a new science advocacy campaign in January. Titled "1010 in 2010", we are determined to get a minimum of 1000 (plus a few to spare) "data-sets". We need 1000 disease history/medication experiences recorded so that the numbers are (statistically) significant to define treatment opportunities. That’s you all!

This data will be used when our MAP and P/P experts from around the world gather at the NIH in Bethesda in the Fall of 2010 to define consensus and advise on protocols.

Now, all this data collection will be gathered in an online survey -- no phone calls, no appointments (unless you want), just log in, enter your meds, improvements and flares -- at midnight, in your pajamas, on your cell phone, whatever works for you. Watch the IPPF website as the numbers rise and find out interesting facts from the data! We appreciate what you contribute to helping everyone have access to better treatments!

...continued from TREATMENTS, page 1

We need your help in the coming year! We have lofty expectations, but in order to help our researchers close in on a cure, we need your input. Our registry is in the works to give scientists the data they need to help identify trends, look for commonalities, isolate triggers, and more! But we need raw and statistical data for them! Stay tuned...more to come!
It Takes a Community...

The winter holidays and the New Year are approaching. There are multi-hued lights, decorated trees, candles, menorahs, holiday music and wreaths. This is also the time of the year for television, mail, radio and other requests for contributions to various charities—not to mention races for cures, walkathons, swim meets, Saint Jude and other Children’s Hospital special requests for money and gifts, plus people (often in uniforms or Santa costumes) on street corners ringing bells and asking people to reach into their pockets and wallets for contributions.

For most people there are memories of past holidays and family/friends, some who are no longer alive. These memories may be happy and/or bittersweet. EVERYONE has at least one significant holiday story. In the P/P community people often share personal stories of tragedy and triumph. Isn’t it amazing for these rare diseases to be so rich in the fellowship of patients and caregivers?

In my psychology practice, I have seen and worked with many patients with chronic illnesses. Many of these diseases do not have “races-for-cures” or huge research grants. Also, like P/P, many diseases don’t even have recognizable names!

Eight years ago, after almost nine months of symptoms, this “newbie” searched medical literature and libraries to find out more about this new and unknown disease of Pemphigus. One call to my graduate student son yielded more information in five minutes than several days of intense personal investigation. I was given a link to a P/P discussion group found on the internet! After all this time and all the futile attempts to even get doctors to take the problems seriously, we not only found the disease on the internet, but also a discussion/support/educational group of fellow patients. Reading and connecting with people living with the same disease and who had positive outcomes was an amazing experience; Hermien (The Netherlands); Carolyn (UK); Oceane (France)...we are truly a worldwide community (http://community.pemphigus.org).

One of the first emails I saw was from Skip (who is in remission, but who continues to contribute to the IPPF and the community with his remission website at www.pemphigusremission.com). I was nervous about eating a Thanksgiving meal, but Skip sent a holiday greeting with specific advice for “newbies”. He wrote to the group about his first Thanksgiving with PV and how he just hoped he could swallow some soft mashed potatoes at the dinner. Those words of empathy and hope for others who were currently experiencing these symptoms did not fall on deaf ears. Through local support groups and the IPPF, there are numerous past and present successes. Future successes will follow as the “community” and Foundation continue the IPPF initiatives of the registry, HMP, tissue-bank, and fellowship. This is the season when people talk more about faith, hope and charity. Charity does begin at home, inside of our community. Please donate whenever and whatever you can. Remember that for the rest of 2009 any amount donated to the IPPF will be worth double, thanks to the generous Unger Family challenge.

Best wishes for the holidays and for 2010!

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.
The Long Journey to that Sweet Place Called "REMISSION"

by Sandra Gittlen
Pemphigus Vulgaris Patient and Freelance Journalist

"From everything we know about pemphigus vulgaris, you're in remission."

I just stared at the doctor in disbelief. I think I actually said, "You're kidding me, right?" Probably not the best response. But he smiled, as did the other two doctors in the room, and said, "No, I'm not kidding."

It took me till I left the appointment, got in my car and was stuck bumper-to-bumper in Boston traffic to realize that I had done it. I had licked this insidious disease – well, as licked as an autoimmune disease can get. Anyone who has battled one knows that there is always the chance that it will rear its ugly head again – "not curable, just treatable," is the refrain we all hear way too often.

But for me, the word "remission" was just as good. Medically, according to my dermatologist Dr. Arturo Saavedra-Lauzon, who practices at Brigham and Women's Hospital, remission in pemphigus vulgaris means three things: There is no clinical evidence of active disease or true acantholysis, a breakdown of the cell layer of the epidermis; my B cells, which had been taken to zero through a 12-treatment course of Rituxan®, had recovered to normal in the absence of the disease; and no IgG antibody is noted on my indirect immunofluorescence tests.

Ironically, it had been six years almost to the date since I had first noticed something going horribly wrong with my immune system. In early 2003, after what seemed like the longest five months of my life, my mother passed away. At the time, I was an editor for a computer magazine, zig-zagging across the country developing and leading one-day tech seminars. Some weeks, I'd fly to California and make my way back East, stopping to do classes in three different cities in three days. It was a grueling schedule, made even more hectic as I tried to spend as much time with my mother in a Pennsylvania hospital as possible.

I continued that pace through the summer. Then in the fall, I decided to take a break and go to London with some friends. However, it ended up being my mental and physical breaking point. On the flight home, I noticed red rimming around my eyes. I called my internist when I got home and he told me I must have gotten "pink eye" or some other virus during my trip. Within days, my eyes were no longer just rimmed with red, they were downright bloody-looking and, what I now know were blisters and lesions, had started to appear in the mucosa of my nose, gums, lips and throat.

I was peppered with blisters to the point I couldn’t eat. They were quickly marching their way toward my voice box, which meant I couldn’t talk, so I was placed on short-term disability. Also, we still didn’t know what I had and had to assume it could be contagious.

Finally we thought we were on to something, we just didn’t know what, because the doctor prescribed a short course of high doses of Prednisone. Of course, once I started on the Prednisone, the lesions started to clear, so I returned to work and we all thought I had been cured. How Continued on page 14...

Autumn Brings PEM Friends Together

by Carolyn Blain
PEM Friends (UK)

On November 6, 2009, the UK’s PEM Friends met for their regular Autumn Lunch which is always held in London. As usual, it was in Peter Jones, Sloane Square. The management is always extremely helpful and we have all the space we need for a gathering of between 12 and 20 people, and are never hurried or bothered in any way.

This year’s gathering was as enjoyable as ever, although at the last minute five people sent text messages to say they couldn’t make it. We were nevertheless a party of fourteen and as ever, new friendships were forged and old friendships rekindled.

It’s always so helpful and reassuring to be with people who understand what it’s like to have active pemphigus or pemphigoid. Those attending a lunch for a second or third time exhibit such an improvement in their bearing, demeanour and self-confidence. I believe this comes from having developed a greater understanding and knowledge of their condition and more importantly, having met up with others in this unique club!

Dr. Jane Setterfield, who has both private and NHS patients in London, was our guest. Unfortunately she was held up at the hospital and couldn’t join us until fairly late on, but those still present had a most illuminating chat with her. As with Dr. Karen Harman, Dr. Setterfield is so generous with her knowledge and answered all our queries in great depth.

From PEM Friends funds, the guest dermatologists are given a £50 Marks & Spencer Gift Voucher as a token of our appreciation.

By Carolyn Blain
PEM Friends (UK)
Patient Doctor Meeting

FRIDAY, APRIL 30 - SUNDAY, MAY 2
SHERATON SOCIETY HILL HOTEL
PHILADELPHIA, PENNSYLVANIA
GET PAID $$ FOR YOUR PROJECT AND FREE REGISTRATION TO THIS YEAR'S MEETING!

Do you have an idea that can create awareness among doctors, dentists and nurses?
How about a way to reduce misdiagnoses or help patients connect with others?
Even if you don’t, NOW is the time to start thinking and put your ideas to work!

The IPPF wants to support and encourage our committed members to make a difference in their community! These grants will enable passionate people in our Community to dream up and implement innovative ideas for projects that make a difference.

The IPPF is giving away $500 to support an inspiring project in your community plus free Registration Fees for the 2010 IPPF Annual Meeting!*

Selected entrants are to make an impact in their community by coordinating a project with the $500 they receive from the Foundation. For more information and complete rules, visit www.pemphigus.org/500grant today!

* Actual amount of grants awarded will depend on the number of complete and qualified packages received.

In order to provide winners with ample time to make Annual Meeting arrangements, we ask that COMPLETED PACKAGES BE RECEIVED BY FEBRUARY 19, 2009
Recently, Richard Schwartz, a terrific person, my friend, and a friend to the IPPF, passed away. Richard had a very bad case of pemphigus when we first talked many years ago. But no matter how difficult a time he was having, he always was hopeful and positive.

For several years, Richard led the Houston Support Group. Several years ago, I visited with Richard and Karen during a support group meeting. They were so gracious and offered me a room in their home, to stay while I was in Houston. On a day off, he showed me around Houston and the NASA Space Center. We had a terrific day. Even after the group disbanded, Richard was always there to help others.

For many years he was in remission – had no disease, and was on no drugs. Unfortunately, he developed bladder cancer. When the IPPF started the Health Management Program, Richard called me and said he wanted to be a part of it even though he was still in remission from his pemphigus. I was so happy to hear from him, but in his always upbeat, matter-of-fact manner he told me about his cancer. I was very sad to hear about it, but he assured me that he was okay and that they had gotten it all.

Karen, Richard’s wife, contacted me in October 2009 and told me that Richard had passed away. I cannot say how sad I was to hear that news. He was such a vibrant personality and just a great, real guy. I asked her if I could write a memorial to him for the IPPF Community. Karen wrote this to me:

“He really cared so much about the IPPF. When he was first diagnosed we felt so alone. It seems that so many of the wound care treatments were basically trial and error. We were very lucky to be in Houston at this time and under the wonderful care of Dr. (Robert) Jordan, but as far as at home care we pretty much on our own.

It was a terrible few months and we so wished that there were more people out there to talk with. Richard wanted so much to be a help to anyone who was diagnosed and needed questions answered...not medical, but everyday questions on living with the disease. He often went to people’s homes and visited with them and also talked on the phone or by e-mail to people all over the world. I know it would mean a lot to him, as it does to me, for you to write a Memorial to him. He always was a supporter of the Foundation, as I will continue to be.”

I, as I know many of you do also, send Karen and her family our sincerest condolences. Richard helped me and many others. His family can find comfort in knowing how many people truly admired Richard.

I know that I do.

In Memory,

Janet Segall

Remembering Former Houston Support Group Leader, Richard Schwartz

by Janet Segall
IPPF Founder and Friend

TOP: Richard Schwartz was always full of life and brought his “matter-of-fact” persona everywhere he went. His Texas-sized heart was matched only by his direct, and honest way. These traits were a perfect fit for leading a support group dedicated to pemphigus and pemphigoid patients.

BOTTOM: Richard, back row, third from the left, poses with the Support Group and IPPF leadership in 2004 at the IPPF Annual Meeting in Las Vegas, NV. Janet Segall (next to Richard, back row, fourth from left) was a dear friend of Richard and Karen for many years. While the Houston Support Group disbanded, Richard still managed to help out newly diagnosed patients regardless of their location.
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: Donate to the IPPF Join the HAYP Get involved! Smile!
Capture the Learning: How Journaling Can Help In and Out of the Doctor's Office

by Penney Armstrong
Caregiver

This article is to share our experience with numerous doctors in our quest to obtain a correct diagnosis and supporting treatment for my husband’s noted condition. I have a true passion in sharing both the positive and the obstacles we have encountered in our roller coaster ride into the pemphigus journey.

When I look back, I can remember the exact day and time when I received a confirmation phone call advising that the results of Joel’s biopsy was – Pemphigus Vulgaris. Please realize that this was the third diagnosis that we had received within a three month period and I was slightly leery as the two previous diagnosis and required medication(s) and treatment(s) had not been successful.

The Doctor was emphasizing what to watch for, medications to take, side effects of the medications, foods to eat and foods to avoid, the seriousness of this illness and the list goes on – and I stopped comprehending all this information when she stated “life threatening”. Of course, I had to ask her to repeat a couple of things and that is when I realized I need to write this down as it is too much to digest at one time and I needed something as a point of reference – thus the implementation of our Pemphigus Journal.

The Journal has been at every office visit and is close by for all phone call(s). Often times the Journal is recognized by the doctor(s) as a great idea due to the variety of medical personal that we interact with. This journal provides the various dates, results, and recommendations made during the office visit. It serves as a reference guide when the physician quizzes us as to when and the results of our latest lab tests, and it contains the current medications and dosage, which physician prescribed that medication and the validation for that medication.

Often times, we have been educated on “home remedies” to try that could/can assist in our battle with this “new” auto-immune disease and that info is acknowledged within the Journal.

This Journal not only captures the doctor’s visits but also contains our findings from the various dressings/bandages and lotions/gels that have been recommended. I have also documented my husband’s emotions in his battle to accept this life altering disease. This disease not only impacts you physically but emotionally also. Doctors need to know this and assist in treating that side of the disease also.

While utilizing the Journal, we have taken photos from the beginning of the diagnosis to use as a resource to track our progress. Unfortunately, the photos have also provided validation when there has been no progress and to assist the doctors in determining and recognizing when next steps are needed. We have been fortunate in having the opportunity to work with a Peer Health Coach from the IPPF. The results from these meetings have been documented and shared with our various Doctor’s so they can use these findings in their quest to determine the treatment for Joel.

In September 2009 we experienced an ugly side of pemphigus when Joel was admitted to the hospital with the diagnosis – “he is on a teeter-totter” and could go either way due to the serious side effect from this disease.

When someone is given that type of information, your head starts swimming and you feel like you are on overload. I remember calling his daughter and explaining the life threatening situation. She arrived shortly, followed by his son, Brad. We had numerous conversations with numerous doctors and through this all – Brad and Ann both commented – “Thank goodness for Penney’s Journal!” as it contained numerous details from all previous doctors’ visits.

My husband, like others with pemphigus, has encountered many trials and tribulations along the way. On a positive note, while in the hospital, we were introduced to the “Wound Care” Specialist – what a fantastic group. They applied dressings that aided in speedier healing - again all captured within the journal.

Our Pemphigus Journal has and will continue to be our life-line to capture and share our experiences and learning’s while battling this disease. Before we leave for our doctor appointments, Joel always checks with me and asks – “Don’t forget your journal”. He too, like me feels it contains a mountain of information.
Hi, my name is Lillian Dodd; I am a freshman at Cristo Rey High School here in Sacramento. Once a week I come in and work here at the International Pemphigus and Pemphigoid Foundation to offset the cost my tuition for school. I update the News and Information section of the website (www.pemphigus.org/news) by adding new articles. In the few months I have been here, I have learned so much about these diseases. Pemphigus is an autoimmune skin disease with symptoms like 3rd degree sunburns or really bad blisters. Pemphigus can spread from you arms, eyes and even the mouth.

When I was at school and they told me where I was working at IPPF, I said "What is that?" When I first saw pictures of pemphigus and pemphigoid I thought to myself, "How painful and sad to have people out there in the world with this on their body and skin." This doesn't just affect them -- it affects everybody around them. I have learned that these diseases affect everybody in a different way. Generally, only middle aged or older people get this condition. However, Pemphigus affects people of all races, although Ashkenazi decent may be at higher risk. There are 3 ways a doctor can tell if you have pemphigus: visual exam, lesion biopsy, and direct immunofluorescence.

Some of the things I do here are edit/update the website and “ping” them out. I use www.ping.fm to send the articles out to Twitter, Facebook and MySpace. When I send these articles out, our "friends" out there can understand more about what we do and the resources available to them. I'm what you can call an "office assistant". I also answer phones, reply to emails, copy, fax and mail out letters.

Like most of my generation, I thought knew a lot about the internet, but teens know absolutely nothing compared to a lot of people. Some of the things I have learned here are the "behind-the-scenes" of the internet. If it weren't for my bosses, Molly and Will, I never would have known the internet like I know it today. I definitely would have never understood things such as coding, decoding, HTML, CSS, etc. And I didn't realize how much of an impact I made on the patients just by updating the websites every week.

I manage the IPPF Facebook, Myspace, and Twitter accounts. I help get the IPPF name out there to raise money and help find a cure for these diseases. Over the next couple of months I hope to gain more HTML knowledge and experience. I think this will help me later down the road because I want to become a teacher or something to do with working with young children. I think this will help me with creating interactive learning tools. I think knowing HTML will improve my chances at getting a job because as time goes on we are becoming more internet and technology savvy.

by Lillian Dodd
Cristo-Rey High School, Sacramento CA
IPPF Intern

Working at the IPPF: 101
PV, HTML, BP, CSS, MMP... if being a teenager wasn't already hard enough! How do you even pronounce it?
ever, as I tapered off the Prednisone, the lesions reappeared and this time, they were worse, blanketing not only my internal mucosa, but also my stomach and leg. The infectious diseases doctor said he couldn’t help me and sent me on my way. Again, I was sidelined from work and out of luck. Upon my sister’s urging, I returned – as a last-ditch effort before the ER – to my internist.

He concluded that because it was now visible on my skin, maybe a dermatologist would be able to help and sent me to Dr. Jay Cohen at Newton-Wellesley Hospital near Boston. Luckily, Dr. Cohen had just recently seen another patient with pemphigus vulgaris – his first in years, he said. He immediately took a biopsy of my abdomen lesions and confirmed the diagnosis with Dr. Razzaque Ahmed, an expert in this field. He called Dr. Ahmed personally and asked him to see me as soon as possible. This was around Christmas of 2003. By New Year’s, I was a patient with Dr. Ahmed. I will be forever grateful to Dr. Cohen for taking such a personal interest in my case and changing the trajectory of this disease’s effect on me.

I tried resuming my work travel schedule but within a few months found it too demanding and I quit to become a free-lance writer. As an aside, that was probably the best thing that ever happened to me. It was a lifelong dream fulfilled. As my wise nephew said, “See, there have been some good things about battling this disease.”

The last straw for me was when the entire lining of my throat sloughed off in a single piece of tissue. The pain was so excruciating that I felt defeated. I had been on IVIG for years at that point and I seemed to be in a stalled pattern that would not let me off the Prednisone. Finally, we decided that I would undergo the Rituxan protocol that others were seeing success with. I tolerated it well in tandem with IVIG and was able to taper off the Prednisone completely. Although I was doing comparatively better, I still had blistering here and there and my gums were bright red and pulpy.

I didn’t care, I felt good. I had even been working out with a personal trainer and thanks to tapering off the Prednisone and eating better, had lost the bloating caused by Prednisone. My energy level had also rebounded so I poured myself into my niece’s wedding, took another niece and nephew on a cruise to Alaska; and ran a 5K – all within one summer.

I don’t have to tell you what happened next. I suffered a pretty massive relapse. One that crushed me physically and mentally. Where I had almost been finished with IVIG – one more round – I suddenly was back to every four weeks after having made it to 14-week intervals and I was back on Prednisone. And the worst part, I had done it to myself. So I decided from that point on – no extra stress and only low-impact exercise. When my health insurance forced me to switch dermatologists, I took the opportunity to start doing IVIG closer to home -- a 10-minute drive to a nearby hospital infusion clinic vs. a two-hour drive into Boston. That alone relieved a tremendous amount of stress.

And amazingly, over the past few months, I’ve had no lesions and my gums are the beautiful pink/salmon color that I had admired in others.

So that brings me to today and that wonderful word “remission.” As you can see, it’s been a long journey and I have every right to be skeptical of how long this will all last, but I’ll take what I can get.

Sandra Gittlen is a free-lance business, technology and lifestyle writer in the greater Boston area. She can be e-mailed at sgittlen@verizon.net.
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