

Quarterly

The Journal of the International Pemphigus & Pemphigoid Foundation



TO ATTEND THE
2015 PATIENT CONFERENCE



**TOP 10 REASONS TO ATTEND
THE PATIENT CONFERENCE**

more on p. 4

**PSYCHOLOGICALLY SPEAKING:
PLANTING SEEDS**

more on p. 7

**2015 RARE DISEASE DAY:
D.C. TO CA**

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Do you know what season is almost here? Tax Season? Well, yes, but that's not it. Spring? You're getting warmer. Baseball Season? Close!

It's Conference Season!

I am very excited for the IPPF return to New York for our 2015 Patient Conference. Our host, Dr. [Annette Czernik](#), and the Conference Committee have been hard at work developing agendas, lining up speakers, and making sure the weekend is one to remember. This patient-centered event gets better each and every year! I know -- this is my 10th one!

Thanks to long-time IPPF sponsor [Biofusion](#), our Conference Kickoff will be at Yankee Stadium. Afterwards, we can watch one of baseball's greatest rivalries from our reserved, lower-level, left field seats as the Yankees host the Mets. This special event is part of the [Complete Conference Package](#) (\$170) and you can bring a guest (\$40). There is still time to register, but space is limited, so I encourage you to register today (*see pages 18-19 for details*).



William Zrnchik, MBA, MNM
IPPF Chief Executive Officer
will@pemphigus.org

Stepping up to the challenge of governance and leadership, I'm proud to introduce three new members to our Board of Directors: [Michelle Atallah](#), [David Baron](#), and [Todd Kuh](#). If you will be at the Patient Conference, stop by the BOD Booth and say hi (*and see how you can become a Director!*)! Welcome to the team!

Join the IPPF and 2015 Patient Conference Kickoff sponsor Biofusion at Yankee Stadium Friday Night!*

*See page 18 for details

Since 2008, my good friend [Rebecca Oling](#) has served on our Board of Directors helping out any way she could. During that time, she has been instrumental in our awareness, support, and education programs. From policy and procedure development, to newsletter edits and contributions, to video testimonials and live TV interviews, she has been the trusted voice of the patient. In 2014, Rebecca received the IPPF Founder's Award for her unwavering dedication to the P/P community. After seven exciting years, she has stepped down from the Board. *Fear not!* She is still very active on Facebook and with the [Email Discussion Group](#). Please join me in thanking Rebecca for her hard work and commitment to our Pemphamily. *Thank you!*

You're holding in your hands one of my favorite *Quarterly* issues ever! If you need a reason to attend the Patient Conference, we have 10 of them (p. 4). Social media is a great source of information and inspiration (p. 5). Two patient stories are in this issue and emphasize the need for P/P awareness (p. 6 and 9). Spring is a time to plant the seeds of change (p. 7). See how autoimmune blistering disease research helps P/P patients (p. 8). Our Houston Support Group is building momentum (p. 17).

If you haven't registered for the Conference, we still have room for you! [ippf](#)

Questions? Comments?

If you have a question for the IPPF, want to comment on a previous article, or recognize someone in our community, contact us and we'll get you an answer or response... and maybe use it in a future issue of the *Quarterly*!

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TOP TEN

reasons to attend the 2015 Patient Conference

Victoria Carlan

My name is Victoria and I live in Ottawa, Ontario, in Canada. I was diagnosed with pemphigus vulgaris in 2004. I was 39 and a very active, healthy person. It was a long, frustrating, sometimes frightening journey to remission. I spent close to six years on various medications and treatment therapies before finding the right combination that helped me to get to my “new” normal – a life without medication or lesions.

One of the things that I did for myself that I can say truly helped me was to attend the IPPF Annual **Patient Conference** when I was first diagnosed. It was a life-changing experience for many reasons, including those in the list below.

I attended my first conference in 2004. I believe it was one of the best things that I did for myself and I believe it made a difference in how I managed my health. I came away better informed, more hopeful, and ready and willing to “drive the bus” when it came to my health. The experience was a confidence booster which ultimately helped me have a better relationship with my dermatologist and other healthcare professionals. I have attended many conferences since (although not all) and they have all been worth my time and effort.

If you attend the conference, you will . . .

1. **Learn a lot in a short period of time.** For the most part, presentations are in plain, nonscientific format, making it easy for people to understand. The conference has a variety of sessions on a wide range of relevant issues presented by experts in the field. It's better than a Google search or short visits to your dermatologist.

2. **Broaden your understanding of promising new developments.** Many presentations will focus on encouraging developments in research and treatment therapies. With this information, you can return home and have more meaningful conversations with your dermatologist or other healthcare professional about treatment options.

3. **Meet some of the best researchers, dermatologists, and physicians in North America.** The access to medical professionals experts in their field is one of the best offerings of this conference. Because the conference is of a manageable size (i.e., 100 to 200 attendees) and conference organizers focus on bringing in the most well-respected speakers, it is easy to have conversations with these individuals. In fact, these conversations are welcomed.

4. **Meet others at your stage of the disease.** While many people attending are newly diagnosed individuals, a wide range of people, who are at different stages of the disease and from different parts of the US and Canada, attend the conference. You will learn a great deal from others. For example, at one conference, I learned about new types of bandages and how to apply and remove them. Who knew! But, what a help!

5. **Feel less alone.** At every conference, I found many people open and willing to share their stories. It made me feel not so alone. These people “get it.” Whether you are a patient or caregiver to a patient, you will find kindred spirits at this event.

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The Importance of Social Media in #raredisease

Like • Comment • Share •  1,487



Noelle Madsen

In the last decade the presence of social media has exploded. Social media has become mainstream in society for multiple reasons. First and foremost, *it's free*. Second, it helps those who need to get information out to a mass audience very quickly and easily. Whether you love or hate social media, one thing that we can't deny is that it isn't going anywhere anytime soon.

In fact, for rare disease nonprofit organizations like the IPPF, it is a huge benefit for us to be on social media, as well as to have our pemphigus and pemphigoid community present on social media.

For those affected by a rare disease, social media is great for creating awareness, providing information, and most importantly – to create a support network for patients.

Awareness

By "liking" our social media pages and/or by having discussions about pemphigus and pemphigoid on social media, you are helping to create awareness for these rare diseases. The numbers of followers we can get on our social media pages is directly linked to the scale and scope of the interest we attract from companies in the rare disease industry.

Every time that you "like" or "share" one of our posts you are personally helping to create awareness of pemphigus and pemphigoid. Even if one more person knows about pemphigus and pemphigoid who didn't before, that is a victory.

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For Molly, the path to a pemphigus vulgaris (PV) diagnosis involved **over 10 months** of rotating doctors, frustrating misdiagnoses, and unnecessary drugs.

Delayed Diagnosis

Patrick Dunn

Molly's journey began in early 2014 when she noticed loose skin and pain under one of her bottom teeth. As time went on, her gums began to bleed regularly. The loose skin and blisters became lesions that progressed around her teeth and the base of her gums. After every meal, the skin shifted, causing new areas of pain.

Eventually, Molly LaFata's lesions spread to her upper gum line, her esophagus, and the sides of her tongue. The blisters also spread to Molly's back and stomach. On her back, the lesion opened and was extremely sensitive.

While trying to manage her symptoms, Molly saw two dentists, one oral surgeon, two dermatologists, and one general practitioner. She was misdiagnosed twice as having herpetic outbreaks, and there was speculation of her having lupus and hormone imbalances. She had multiple blood panels performed, and she was treated with topical and systemic ste-

roids, two rounds of antibiotics, and herpes medication. All of this provided little relief, until one of Molly's dentists remembered a case he had seen 30 years prior while practicing in the Army. He wrote down two possibilities – lichen planus and pemphigus vulgaris (PV) – and advised Molly to have a direct immunofluorescence biopsy performed.

At home, Molly researched both diseases. An Internet search for "pemphigus vulgaris" led her to the IPPF website. "The Pemphigus Foundation's site is and was a godsend," Molly said. "It was there that I saw a patient video that spoke to



me." This video featured **Becky Strong**, an IPPF Patient Educator. The video detailed Becky's diagnosis process, which was very similar to Molly's experience.

After viewing the video, Molly contacted the IPPF and obtained a list of doctors with experience diagnosing and treating PV.

Three days later, Molly had a biopsy and an enzyme-linked immunosorbent assay (ELISA) performed. Soon after, on January 7, 2015, she received a call that the biopsy results were conclusive. **She had PV.**

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PLANTING *Seeds*

Terry Wolinsky McDonald, Ph.D.

Spring is a time of renewal and growth and therefore change. Yet there is never a better time than the present, despite the season, to pursue change.

For many people it can be a mindset. It may be easier to allow yourself to continue in your familiar pattern (maybe a rut) even if that is not in your best interest, than to actually make changes. For most people, change – although inevitable – is difficult. Even if your status quo is not great, change can feel scary and overwhelming.

How many people decline to go out stating they will do those things when the weather breaks, or some such comment? I wish I had a dollar for every patient I have heard say that. I would be very wealthy. In my professional experience, the answer is that not very many actually do follow through with a commitment to change a behavior or a life situation unless nudged along with small steps. For every one of my patients who has cross country skied to an office appointment (in Pittsburgh!), there are probably six who have canceled. What motivates some people to keep moving forward and not let external factors hold them back?

The human brain is very complicated, but also predictable in many ways. When asked to make

a prediction in court, psychologists cite the fact that they do not have a crystal ball. When asked for the best professional guess, the answer is generally that the best predictor of future behavior is past behavior. One does not have to have specialty training in neuropsychology to see patterns in people. This does not, however, mean that most people are rigid and cannot change.

A lot of people do not want (or perhaps have severe physical limitations that do not allow them) to get dirty and plant the seeds for a new garden. This could be because of physical limitations on exercise or the necessity of avoiding specific foods. Yet when presented with a beautiful blooming garden, most people do appreciate the colors, scents, and sheer beauty. Even one living and thriving plant can enhance personal moods and energy levels.

I vividly remember my second year of pemphigus, when I was still experiencing devastating symptoms. My own choices were to live and work to the fullest. I did not cancel my planned visit to see one of my closest friends in Europe. I did, however, request that rather than visiting my favorite Paris museum to view my favorite Monet paintings.

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Autoimmune Blistering Disease

Demographics and Epidemiology

Mirella Bucci, PhD
Secretary, IPPF Board of Directors

The body's immune system is designed to attack foreign invaders as well as its own tissues if it detects damage, such as with cancer. Because the ultimate goal of the immune system is to kill cells, it must act in a very precise way only against these targets. When the immune system's own detection system goes awry, as it does in autoimmune diseases, the body's own normal tissues are destroyed. Such a confused immune system underlies diseases as diverse as type I diabetes (DM1), rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), psoriasis, and multiple sclerosis (MS), as well as the pemphigus and pemphigoid (P/P) diseases.

In several recent studies, researchers have found connections between pemphigus vulgaris (PV) and specific autoimmune diseases. They have also examined the geographic distribution of PV, pemphigus foliaceus (PF), and bullous pemphigoid (BP), and have examined the differences in disease prevalence between males and females. Collectively, these studies, highlighted here, help shed light on the demographics and epidemiology of these diseases.

Two of these studies, one from a group in Cairo, Egypt (*The Journal of Dermatology*, doi: 10.1111/1346-8138.12676), and another from a group in Antalya, Turkey (*Archives of Dermato-*

logical Research, doi: 10.1007/s00403-014-1531-1), looked at the geographic distribution of PV, PF, and BP. The Egyptian group, led by Dr. Marwah Saleh, focused on PV and PF prevalence in 22 Arab countries between the Atlantic coasts of northern Africa and the Arabian Gulf, while the Turkish group led by Dr. Erkan Alpsoy focused more broadly on PV, PF, and BP, the most common autoimmune blistering diseases, throughout the world and also reported on age of onset of these diseases. Both of these studies were done by collating data and some conclusions from multiple published studies.

In Dr. Saleh's work, there were some curious observations. For instance, she noted that PV was more prevalent than PF in several countries (including Egypt, Sudan, Morocco, Syria, Jordan, Iraq, and Algeria), while PF is more prevalent than PV in others (Libya, Mauritania and Tunisia). Pemphigus is rare, or at least rarely reported, in Qatar, Lebanon, and Bahrain. In at least one country, Morocco, there is variation from region to region, with PF being prevalent in Marrakech, the second-largest city, while in Casablanca, the largest city, the prevalence of PV and PF is nearly the same. Finally, in the Arab world, pemphigus diseases are more common in females (male-to-female ratios between 1:1.1 to 1:4.1), except in Saudi Arabia where the ratio was 2.2:1 in favor of males. Previous epidemiological studies have observed a similar skewed prevalence towards females, with some exceptions: besides Saudi Arabia in the Arab world, China also has more male diagnoses than female.

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Mid-Journey Musings

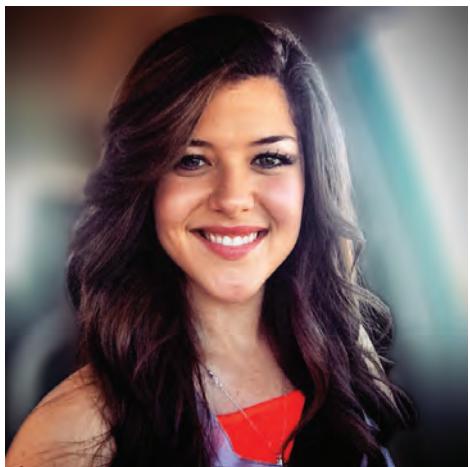
My diagnosis story

Hannah Heinzig

My name is **Hannah Heinzig**, and I am 24 years old and recently diagnosed with pemphigus vulgaris.

I studied nursing at East Central University in Ada, Oklahoma. My hopes and dreams were to be a missionary nurse overseas in third world countries, providing health care to those who cannot afford it or don't have access to good health care.

As a college student, I was very active on campus with international students and Christian campus organizations. I wanted to change the world by loving one human at a time.



Hannah Heinzig, BSN, was diagnosed with PV after a lengthy and discouraging process. As a medical professional, she wants to share her story with others in the medical field so future patients are properly diagnosed — and begin treatment sooner rather than later.

Helping Others

Local blood drives love to use college campuses to request help. I myself donated on multiple occasions.

One day at a blood drive, there were representatives who were raising awareness for the **National Bone Marrow Foundation**. I listened as the speakers told us about the new research being done, and how with a quick swab of your cheek and some necessary paperwork, you could become a registered member, and a possible bone marrow or stem cells donor for cancer patients needing healthy cells. I was intrigued, having always been willing to help save a life.

Two years passed and I completely forgot about that day until I was in my junior year of nursing. We had learned in class about the importance for people with various cancers of stem cell and bone marrow donation from nonfamilial relations. The professor asked if anyone in the class had registered as a bone marrow or stem cell donor, and I remembered I had registered two years prior.

It also became apparent that I was the only one in my class of 75 students who was registered.

The more I learned about donating my potentially lifesaving cells, the more I was excited to be a possible match for someone. I prayed that weekend that if God wanted me to be a healthy donor for someone, I was ready and willing.

One week later, I received a call from the **Oklahoma Blood Institute** saying I was a possible match for a 37-year-old female with acute lymphoblastic leukemia. My heart began to pound as I remembered my prayer one week prior. Long story short, I was the perfect match and had the privilege to give my healthy stem cells through a process called apheresis. This process required me to receive subcutaneous injections of Neupogen® for 5 days prior to the retrieval of my stem cells.

Neupogen® forces your bones to produce large quantities of healthy stems cells into the bloodstream. After the five treatments, doctors draw blood, filter out the stem cells, and return the filtered blood back to your body. The patient needed approximately 5 million stem cells and I donated 6.4 million. They kept the patient anonymous, but were able to tell me that she survived and was do-

CONTINUED ON PAGE 14...

The Turkish study also highlighted several epidemiological observations that were noted previously. For instance, the frequency of PV and PF among people with Jewish roots is nearly eight times that of people of other ethnicities. Overall, the incidence rate of all of the P/P diseases is 14.5 per million per year, with at least two-thirds of these being PV. Depending on the exact geographic region, the incidence rate number varies from between 0.5 and 16.1 per million per year. As in the Egyptian study, the Turkish study also noted differences in the prevalence of PV versus PF. In Brazil, for instance, the prevalence of PF is 20 times more than PV.

One curious observation in this study was that the mean age of diagnosis differs between countries. For instance, in European countries, the diagnosis age is on average between 50 and 60, while in the remaining countries in the world, it is between 30 and 50; overall, the worldwide average age of diagnosis is between 40 and 60. Finally, BP, considered an “elderly disease,” is the most prevalent among the P/P diseases in Western and Northern Europe and Singapore. The authors suggested that this could be because the life expectancy is high in these areas, so BP, with its later onset, is more likely to be seen. As well, both the Turkish and the Egyptian study cited work showing that environmental factors such as smoking, cosmetics, and farming were risk factors for the presentation of pemphigus diseases.

Surely, these are curiosities that serve to highlight how rare the P/P diseases are, but to begin to understand how geographic location, gender, and age play into the presentation of these diseases, more research will need to be done at the molecular level to understand the immune system processes that go awry and the mechanisms of cell death that lead to blister formation. Patient samples become increasingly important for these studies. If you've attended one of the annual patient meetings of the IPPF, you may have noticed Dr. Animesh Sinha's group, based in Buffalo, New York, at the meeting, asking for patients and their family members to donate blood. You should consider doing so.

Dr. Sinha's group has been analyzing these samples and have recently published one paper in the British Journal of Dermatology; they have one in press at the same journal that has the same epidemiological

flavor as the Egyptian and Turkish studies described above. The first study (British Journal of Dermatology, doi: 10.1111/bjd.13433) took data from these patient samples as well as data from the IPPF patient registry and from an anonymous patient survey performed on the Internet to look at the “clustering” of other autoimmune diseases with PV. It is well-known that individuals affected by one autoimmune disease often develop other autoimmune diseases and that the likelihood of having an autoimmune disease of any sort is increased if one family member has one or more than one polyautoimmunity or “clustering” autoimmune disease. In its current work, the Sinha group looked specifically at PV and found from the 794 PV patients profiled, 19.6 percent had a second autoimmune disease diagnosis.

Among these diseases, autoimmune thyroid disease, RA, and DM1 are more prevalent among patients with PV than in the general population. PV also clustered with SLE, Raynaud disease and MS. In relatives of PV patients, the frequency of having even one autoimmune disease was approximately 3.5 percent. In the future, it will be interesting to study what common susceptibility genes are at play that lead to the autoimmune disease clustering.

In another British Journal of Dermatology publication, Dr. Sinha's group examined the relationship between age of PV onset and gender. They found that male patients are more likely to present before age 40 than females and that males have greater cutaneous (skin) involvement while females tend to have greater mucosal (mucus membrane) involvement and stronger personal and family history of autoimmune diseases than males: 65 percent of female PV patients report having either another autoimmune disease or a family history of autoimmune disease, while only 43 percent of males do. Overall, they concluded that gender influences disease presentation in PV. These results, as well as the results of the other three studies highlighted here, all point to genetic and possibly hormonal factors that dictate the presentation of the P/P diseases. ippf

Mirella Bucci, PhD, is Secretary of the IPPF Board of Directors and a scientific journal editor living in San Mateo, California. She is a regular contributor to the *Quarterly* newsletter in the “Research Highlights” column.

The use of hashtags (#) is also very important in social media. For example, when you are using the hashtags **#healourskin**, **#pemphigus**, **#pemphigoid**, or **#raredisease**, you are telling the social media world (*which is clearly huge!*) that you are having a conversation about those topics. When someone clicks on those hashtags, he or she will be linked to every post that has used that particular hashtag. This is a great way to show the world that pemphigus and pemphigoid are important topics that need to be talked about.

Information

Social media is also a great tool that the IPPF uses to get information out to a large audience efficiently and at little to no cost. Rare disease nonprofits like ourselves are usually operating on small budgets, so allowing us to use tools like social media is very effective for us.

The pemphigus and pemphigoid community is spread around the globe, so when we need to post information right away it is easy for us to create one post on our Facebook page rather than sending out thousands of emails.

Social media is also a very effective tool when we need to share information with the P/P community that originates with other entities. For example, a company may post a new clinical trial starting for mucous membrane pemphigoid patients. When we see that post, we can simply “retweet” the information or “share” the post.

A similar situation occurs when another patient or caregiver posts a question, new information, or something inspirational. We can

share it very quickly with our community via social media.

Support

Social media is important to the rare disease community for many reasons, but perhaps the most important is to be able to be connected to others affected by the same rare disease as you. For the pemphigus and pemphigoid community, we see many new patients and caregivers being connected to one another every day through our social media pages.

media and haven’t started following us yet please go to:

facebook.com/healourskin and be our fan

twitter.com/healourskin and retweet us to your followers

instagram.com/healourskin to see awesome pictures from our community

pemphigus.org/rareconnect to share your story and to read others in the pemphigus and pemphigoid community.

#healourskin

This also a great reason, again, to use our hashtags! One of the ways that we use hashtags is by using the IPPF’s unique hashtag: **#healourskin**.

You may have already spotted our signature **#healourskin** orange sunglasses. If you post a picture wearing the glasses and use **#healourskin**, others who click on the hashtag will be connected to all others who have used it. Imagine someone, recently diagnosed, wondering who else may have this disease. That person finds us on Facebook and sees the hashtag **#healourskin** being used. She clicks on the hashtag and discovers faces of others who are affected by the same disease that she is. Hashtags can be very important in connecting others together.

If you aren’t on social media I would strongly suggesting signing up for some of the social media outlets available just to become connected with others in the P/P community. If you are on social

Please “like” and “share” our posts on Facebook, “retweet” us on Twitter, and “like” our photos on Instagram.

Don’t forget those hashtags!

#healourskin

#putitonyourradar

#pemphigus

#pemphigoid

#raredisease

Together we can create awareness. Together we can come together to create a better world for pemphigus and pemphigoid patients. 

Noelle Madsen is the IPPF Patient Services Coordinator and lives near Sacramento, CA. She is dedicated to providing support and education to those affected by P/P. She is a regular contributor to the *Quarterly*. You can reach her at noelle@pemphigus.org

We actually drive to Giverny in France and visit Monet's actual gardens. For some reason I found that being in an exquisitely beautiful location actually energized me and helped me to heal. I also found paintings and photos of flowers and trees healing, and I surrounded myself with them both at work and at home. Needless to say this was in addition to, not in lieu of, traditional medical treatments.



giverny.org

Claude Monet's Water Lily Pond was inspired by prints of Japanese gardens Monet collected. The bridge is part of his famed bridge series.

Taking care of your psychological health can sometimes be done with supportive family and friends at this critical juncture; however, this is an ideal time to at least get a psychological or other mental health evaluation. The feelings, thoughts, and sense of loss will likely not be at a healthy place at this time. Talking with a mental health professional, preferably one who understands the psychological aspects of chronic illness or pain, can often nip emotional problems or cognitive distortions in the bud.

Having one or several serious chronic illnesses does not mark the end of living a full life, but rather a new beginning. Planting seeds can be a positive beginning. Of course, seeds need to be cared for and nurtured, which is what people – especially those with pain and/or chronic illnesses – find necessary for their own healing process.

What if those closest to you are unable to handle illness, doctors or hospitals? They clearly will not be the people who attend necessary visits, labs, or treatments with you. You can look for support with others or through a separate, perhaps more formalized support group. However, those people previously closest to you may be able to help in other ways. They can grocery shop, make a bed, cook, clean up, fold

laundry, or take out the garbage. The list of tasks to lighten a patient's load is endless.

Nurturing oneself may mean cutting back on work hours, learning to schedule exercise or massage, eating healthier foods, or just dancing to music like there is no tomorrow! It also includes budgeting wisely – not just your money, but your valuable time and energy. How many times have you agreed to do something that you knew was not in your best interest? Perhaps you agreed so as to not let someone else down. If that person truly cares about you, he or she will understand. If offended, that person is probably best left in the dust. If you have great difficulty saying no (otherwise known as “the disease to please”), try saying, “I don’t want to let you down and would love to be able to say ‘yes’ to your request, but _____.” It can come across more easily that way and also makes the statement more positive. Eventually, saying no when it’s appropriate becomes second nature.

Because I have several autoimmune illnesses, I have had to retrain people in many ways. For example, my husband no longer asks me if I want to take a walk or go to the museum, etc., but rather if I feel up to it. Just changing the way something is said or done can go a long way, and *sometimes just one word can make an infinite difference*.

I suggest if you’re seeking change or even a slight improvement on your emotional situation, that you think of yourself as newly alive – perhaps a flower bud. That bud needs to be watered, to get enough sunlight, to be in a temperature controlled environment, and to be nurtured in order to blossom. You have more control over this than you may have previously realized. You may have heard the saying about how when one door closes, another one opens. I absolutely believe this to be true. However, sometimes the hallways between the doors can be very dark. You may need a flashlight. Personally, I prefer scented candles! Figure out what is most important to you, and slowly but surely take those first small steps in this new and different way of being in the world. Growth does not only happen in spurts. [ippf](#)

Terry Wolinsky McDonald, PhD, is a PV patient, licensed clinical psychologist, and former IPPF Board member living in Pittsburgh, Pennsylvania. She is a regular contributor to the *Quarterly* newsletter in her “Psychologically Speaking” column.

6. **Have an opportunity to give back.** In 2014, almost half the conference attendees were individuals who had reached remission. Like me, they attend to keep on top of whatever new developments are unfolding because, well, you never know. But, more so, I attend to show others that there is hope of returning to some kind of normal life – however you define it. Those who are newly diagnosed really benefit hearing this, as I did at my first conference.

7. **Get some good swag.** The IPPF is able to work with committed organizations and sponsors to provide samples of products that are known to give relief or provide protection to our fragile skin inside and out.

8. **Feel like you have some sense of control.** I think I can speak for most people by saying that most days I don't feel like I have much control of my disease. Medications work or they don't. Flares come when you least expect them or not when you think they will. Attending the conference and reaching out for support, information, and understanding is one of those things that you can have control over.

9. **Find support,** if you are a caregiver. It is very tough to be a caregiver of someone with one of these diseases. You feel as helpless, frustrated, depressed, and desperate as he or she does. You don't want your loved one to suffer and you are hoping for a cure or remission as much as he or she is. The upcoming conference, in particular, will have a number of sessions to help our loved ones better cope and also stay healthy emotionally and physically.

10. **Enjoy a couple of days to yourself.** For those who decide to attend alone (as I have done many times), the conference is a place where you can take a couple of days for yourself in a safe place with others who understand.

I hope to see you in New York this year! 

Victoria Carlan, is a PV patient, business consultant, and Vice President of the IPPF Board of Directors. Despite her PV, she lives an active life and is an avid runner. She lives in Ottawa, Ontario, Canada.

1

Learn — A Lot!

2

Understand

3

Meet Experts

4

Meet Others

5

You're Not Alone

6

Give Back

7

Get Some Swag

8

Regain Control

9

Find Support

10

Enjoy Yourself!

...continued from AWARENESS, page 6

Molly said that she felt “a strange concoction of relief and reality” when she received her diagnosis. “Relief in the sense that my ten-plus month journey to a proper diagnosis was now complete. Reality in that it was no longer guesses and possibilities, but a living, breathing, disease.”

Molly lives with her husband, Chris, and their two daughters in Colorado. They were leaving for a weekend trip to the mountains when Molly got her diagnosis call.

She spent the two-hour drive trying to process the new information. “I remember the rise and fall of emotions,” she said. “The oddest of them was this general feeling of being uncomfortable in my own skin. . . . My body had turned on me, and waves of anger came

and went, followed by feelings of softness and sadness. I felt fragile and unsure.”

Focused on healing, Molly began blogging about her PV experience at www.mollylafata.com in February of this year. She will also be contributing to the IPPF website in the future. “I’m hoping that by writing and sharing my experiences publicly, I’ll attract and connect with others who share this ‘special disease’ with me. In a sense, I’d like to make the world feel smaller. I’d also like to be a resource for anyone looking for answers in determining if they too have PV.”

Unfortunately, Molly’s story of delayed diagnosis is similar to what most pemphigus and pemphigoid patients experience.

Because of this, the IPPF Awareness Campaign was created with the goal of improving the quality of life of P/P patients through early diagnosis. As Molly’s story illustrates, dental professionals have a unique opportunity to shorten diagnosis times. For this reason, the Awareness Campaign encourages dental professionals to “Put It On Your Radar.”

To learn more about the Awareness Campaign and how you can help, visit www.pemphigus.org/awareness. ippf

Patrick Dunn, MFA, is the Health Communications Specialist at the IPPF. He is a contributor to the Quarterly’s Awareness and You column. Patrick can be reached at awareness@pemphigus.org.

...continued from MID-JOURNEY, page 9

ing well. I named her Faith so I could continue to pray for her.

My Disease

The story of my disease begins in July 2011, the day I gave my stem cells. I was told my immune system would be compromised after giving my stems cells because I gave away five percent of my immune cells and it would take approximately six weeks to recover. I was not prepared for two and a half years of suffering with symptoms physicians dismissed as stress.

I immediately developed fatigue, but I figured this as part of my recovery process. I also lived in a college dormitory so I attributed my cold and flu symptoms to a decreased immune system. Then I started having painful bleeding ulcers in my mouth and oozing scabs on my scalp.

I was concerned because I am particular about my oral and scalp hygiene. On a side note, I am a very smiley person, and as soon as I began having visible ulcers in my mouth and bleeding gums, my smiles became fewer and fewer. I was silently suffering.

I didn’t even want to get my hair cut or styled. I was afraid what the stylist would think when they saw the condition of my scalp. I tried every herbal remedy I could think of – from tea tree oil to a special Japanese tar shampoo. Nothing was working. It was time to make a doctor’s appointment, something that I have always dreaded. Yes, I am a nurse working in a hospital emergency room, and so I probably make the worst patient because my instinct is always to self-treat first.

I was silently suffering.

I was prescribed antibiotics, antivirals, and mouth rinses, yet nothing helped. My doctor eventually told me that because I was in nursing school, my symptoms were all due to stress.

CONTINUED ON PAGE 15...

The ulcers were progressively getting worse and my gums were now bleeding and sloughing with the slightest brushing. I called my Oklahoma Blood Institute representative. I asked if giving my stem cells or the Neupogen® could have anything to do with my symptoms. She assured me there were no connections. I was growing hopeless that I would always suffer with these unknown symptoms.

I began having a sore throat and extreme pain when swallowing. I remember one day at work in the emergency room break room when I was crying. I was trying to swallow my own saliva and drink the tiniest sip of water.

Eventually, I was referred to a periodontist. After five minutes, and with a concerned tone only a physician can have, he said I either had leukemia or a rare autoimmune disorder.

I was shocked. How could I possibly have cancer? I gave my stem cells to a woman with leukemia to help champion the cause, not become the victim. I was told my swallowing problem was severe and I needed to seek emergency treatment immediately. The room began to spin and roaring sounded in my ears as it drowned out anything further he might have said.

I was referred to a list of specialists:rheumatologist,gastroenterologist, EENT (eye-ear-nose-throat specialist), and dermatologist. I went from having my symptoms completely disregarded to being labeled a medical mystery. I had an EGD (esophagogastroduodenoscopy) done, only to reveal that the ulcers had appeared in my

esophagus and stomach, the likely cause of my pain from swallowing and eating. I was sent to the EENT who performed a surgical biopsy. The results came back as abnormal. Surely, with a medical diagnosis, you don't want to be considered special: normal is suddenly so appealing.

I was referred to a dermatologist, who took another two biopsies and began to see abnormal smears that resembled pemphigus. He ordered biopsy tests.

I was officially diagnosed with PV on July 27, 2014.

I now had a name to my misery. I also had some answers and immediately began prednisone.

I am a very patient and mild person who has normal eating habits and normal moods. On prednisone, I felt like the Incredible Hulk, and wanted to snap at people, eat everything in the house, and stay up all night exercising.

Helping Myself

I was doing PV research and decided to change my lifestyle. I adopted the vegan diet. Up to this point it has worked wonders for my internal and external health. I have now weaned off of prednisone. My mouth ulcers and oozing scalp have cleared. All that remains are tender and sloughing gums.

I recently tried dapsone for two weeks. It brought my blood count down too low and I almost had to have a blood transfusion, so my periodontist told me to stop. I was waking up in the morning to blue lips and blue fingernails. My resting oxygen saturation was only getting up to 94 percent at work. Climbing two flights of stairs made me nauseous.

Currently, I am working with my periodontist to save my gums and teeth. He wants to try steroid topically on my gums. We hope there will be fewer systemic effects if I just put the steroids on my gums, rather than taking it orally, as with dapsone.

I have made lifestyle changes and left my emergency room nursing position to join a calmer environment in the surgical admissions unit. My family has rallied around me like the loving warriors that they are. Most of all I want to acknowledge my faith in God. Not once did He leave my side. Even when all seemed hopeless and it seemed like the world was crashing down around me, He became my strength, my hope, my direction.

There is no cure right now for pemphigus, but I know that everything happens for a reason, just as it did for the woman who received my stem cells and survived. It was the experience of helping her that helped me reach my diagnosis. I wouldn't go back and change a thing. If I didn't have this disease, I know I would not have this enormous platform to tell my story and give others hope. Some days it seems hopeless, but I know God has a bigger plan for me. 

Hannah Heinzig, BSN, is a registered nurse living in Oklahoma City who is excited to tell her disease and personal story to help others. She is a Patient Educator with the Awareness Campaign. Hannah enjoys hiking, traveling the world on mission trips, telling animated stories, and reading. She can be reached at hannah@pemphigus.org.



Rare Disease Day®



Top Left: Kate Frantz and Liz Starrels at the AMSA Annual Convention. Top Right: Marlis (PV) shares her story with Peter Saltonstall, NORD. Bottom (l-r): Assemblyman Katcho Achadjian (CA D35) co-sponsored California House Resolution 6 recognizing February 28, 2015 as Rare Disease Day. NORD President and CEO Peter Saltonstall shares the Rare Disease Day story with attendees on the steps of California's State Capitol. California State Senator Dr. Richard Pan talk about the importance of advocacy and research.

During Rare Disease Week (the last week of February), **Marc Yale**, IPPF Senior Peer Health Coach, and **Kate Frantz**, Awareness Program Manager, celebrated RDD events in Washington, DC.

Kate and Marc attended NORD's special preview of the new documentary "Banner on the Moon." Patients, caregivers, advocacy groups and patient organizations saw **Cindy Abbott**'s inspiring story. Cindy carries a NORD banner on her adventures to spread rare disease awareness. These included challenging herself to climb Mount Everest and participating in the 1,000-mile Alaskan Iditarod. Cindy's perseverance and commitment to live life to the fullest were very inspiring.

Kate attended the American Medical Student Association's Annual Convention. Two P/P patients, **Liz Starrels** and **Mimi Levich**, shared their P/P stories. Many students had never heard of P/P, or only briefly remembered it from their textbooks. This was a wonderful opportunity to spread awareness and encourage medical students to "Put P/P on their Radar!"

Marc represented the P/P community at the Rare Disease Legislative Advocates (RDLA) conference. An overview of the 21st Century Cures Initiative (energycommerce.house.gov/cures) was provided. Many advocates believe this is the rare disease community's best hope for new/emerging treatments.

Marc met with several Congressional Members and legislative health experts encouraging their support of the **Orphan Product Extensions Now Accelerating Cures and Treatment Act of 2015**, H.R. 971. This legislation would re-purpose existing drugs for rare diseases allowing patients greater access to vital treatments. Marc also attended a symposium at the National Institutes of Health (NIH) celebrating rare diseases research efforts across NIH, the Federal Government and the entire advocacy community.

On March 2, 2015, rare disease patients, caregivers, rare disease organizations, legislators, and industry representatives gathered at the North Steps of California's State Capitol to celebrate Rare Disease Day (RDD). **Will Zrnchik**, IPPF CEO, welcomed the crowd and introduced **Peter Saltonstall**, President and CEO of the National Organization for Rare

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Support Group

News



Houston Support Group

Mary Lee Jackson, SG Coordinator

On January 31, 2015, the Houston Support Group gathered at Bayland Park Community Center in Houston, TX. It was a great meeting with 14 people affected by pemphigus and pemphigoid in attendance, including three new attendees.

I would like to thank everyone who came out to the meeting. It's always good to see our youngest member, [Laten](#), who is nine years old. Our three new members, [Kathy](#) and [Charles](#), and [Marcia](#), were great new additions and added a lot to our meeting.

We gave out three \$10.00 Amazon gift cards. Two were given to members who have had perfect attendance for all meetings, and one was given to the member who came the farthest distance. Mark your calendars for the next meeting on [April 18, 2015](#).

If you live in the Houston area and would like more information on the Houston Support Group, please contact Mary Lee at marylee@pemphigus.org.

...continued from RDD, page 16

Disorders. Peter said, "NORD has been working ... to find a therapy, make sure the pathways are clear, and to make sure that the incentives are there for industry to want to develop drugs for small populations." California Assembly Member [Katcho Achadjian](#) (D-35th) co-sponsored CA House Resolution 6 recognizing February 28,

2015 as Rare Disease Day in California.

Inside the Capitol, [Andrea Vergne](#), rare disease caregiver and advocate, told her grandson's story about living with a rare disease. [Gary Sherwood](#), Communication Directors at the National Alopecia Areata Foundation, inspired attendees to become self-advocates and work with their elected officials. Adding

Southern Florida Support Group

Nancy Corinella, SG Coordinator

On Sunday February 22, 2015, the first Southern Florida Support Group meeting was held in Coral Springs, Florida. Nancy Corinella (PV) hosted the group. Five P/P patients attended and discussed their journeys. People left with a sense of support after finally meeting others with P/P.



The Southern Florida Support Group meeting will continue to meet throughout 2015. If you have any questions about the South Florida Support Group please contact Nancy nancy@pemphigus.org.

DO YOU HAVE A GROUP?

LET US KNOW! It doesn't have to be formal to be a group! All you need is another person, a place to sit, and time to talk. The important thing is to be able to share your experiences and get the support you need. If you want to find others in your area, contact Noelle Madsen at noelle@pemphigus.org.

to the advocacy theme, [Eve Bukowski](#), California Healthcare Institute, echoed the need for patients to self-advocate. Special guest, California State Senator Dr. [Richard Pan](#) discussed the importance of rare disease advocacy and research.

There are over 7,000 rare diseases with 1 in 10 Americans affected (95% of rare diseases have no approved treatment).

Rare Disease Week and Rare Disease Day is an opportunity for the pemphigus and pemphigoid community to advocate for yourself, our community, and all rare diseases.

If you have questions about current legislation or would like information on how you can become involved, please contact marc@pemphigus.org.

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2015 PATIENT AND CAREGIVER CONFERENCE

- Hear P/P experts on key topics
- Meet other patients and caregivers
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- Learn how to manage your P/P
- Share in the experience

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APRIL 24-26, 2014
MOUNT SINAI HOSPITAL

VENUE

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REGISTER TO ATTEND

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COST

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Inform the agent you are part of the IPPF room block at the **Courtyard by Marriott, Upper East Side**

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Must reserve by March 23, 2015

FRIDAY NIGHT CONFERENCE KICKOFF AT YANKEE STADIUM! SPONSORED BY BIOFUSION

JOIN THE IPPF AS THE YANKEES HOST THEIR CROSS-TOWN RIVAL METS.

Tickets are \$20 for conference attendees (*\$40 for one guest*). SEATING IS LIMITED TO THE FIRST 100 PEOPLE. Enjoy over 2 hours of food, beverage, and fellowship in our own reserved area before the game. Watch the game from reserved seating with other patients, caregivers, and members from the IPPF.

This special event includes multiple transportation times from our conference hotel to Yankee Stadium*

*The bus will depart the Courtyard by Marriott approximately 4:00 pm, 5:00 pm, and 6:30 pm for Yankee Stadium. It will depart the stadium approximately 5:15 pm, 7:00 pm, and 10:00 pm for the hotel. Times may change without notice.



2015 Patient Conference Registration Form

April 24-26, 2015
New York, NY

Print Name (as you want it to appear on your name badge)	Organization/Employer Name (Corporate Sponsors Only)		
I am a <input type="checkbox"/> Patient _____ (PV, BP, etc) <input type="checkbox"/> Caregiver <input type="checkbox"/> Friend <input type="checkbox"/> Other _____			
Mailing Address - Street <input type="checkbox"/> Home <input type="checkbox"/> Work			
City	State/Province	Zip/Postal Code	Country (other than US)
Daytime Phone: <input type="checkbox"/> Home <input type="checkbox"/> Work <input type="checkbox"/> Cell ())			
Email: <input type="checkbox"/> Home <input type="checkbox"/> Work			

A portion of your registration may be tax-deductible. Please consult with your tax professional.

JOIN US FRIDAY NIGHT FOR OUR CONFERENCE KICKOFF AT YANKEE STADIUM SPONSORED BY BIOFUSION.

Patient Conference Registration Fees

	Number of People	Total
I WANT IT ALL! Complete Conference Package: \$170.00 per person Enjoy the conference from start to finish! Join the IPPF and Biofusion on Friday night at Yankee Stadium for the Subway classic Mets/Yankees game! Then join your P/P friends at the plenary sessions and workshops on Saturday and Sunday at Mount Sinai Hospital. Also includes light breakfast, breaks, and conference materials. Transportation between Yankee Stadium and the Courtyard New York Manhattan/Upper East Side will be provided. Parking near Mount Sinai is at a reduced rate of \$X per day.	<u> </u> <u>x \$170</u>	
MEETING ONLY! Conference Registration Only: \$150.00 per person You will be registered for all plenary sessions and workshops on Saturday and Sunday at Mt Sinai. Also includes light breakfast, breaks, and conference materials. Parking near Mount Sinai is at a reduced rate.	<u> </u> <u>x \$150</u>	
BRING A FRIEND! Friday Night at Yankee Stadium Only: \$40.00 LIMITED SPACE! ONE PER PAID COMPLETE CONFERENCE PACKAGE. Transportation between Yankee Stadium and the Courtyard New York Manhattan/Upper East Side is provided.	<u>\$40</u>	
Scholarship Donation. Please help someone else attend this year's conference.	\$	
Tax-Free Donation. Help support current and future programs and research.	\$	
Total Enclosed		\$

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Signature: _____ Indicates you agree to have your card charged.

HOW TO REGISTER

OTHER ATTENDEES (as indicated above)

1. Online: www.pemphigus.org/2015conference 2. Phone: (855) 4PEMPHIGUS (855-473-6744) 3. Contact your Peer Health Coach 4. Mail this completed form with payment to: IPPF 2015 Patient Conference 1331 Garden Highway #100 Sacramento CA 95833	(information as it should appear on their badge)		
	NAME	CITY & STATE	DISEASE OR ROLE*

* PV, PF, PNP, BP, OCP, MMP, Caregiver, Family, Friend, Physician, etc.

Registration cannot be processed without payment. Payment must be in US funds. All cancellations must be received in writing or by email to info@pemphigus.org. For cancellations postmarked on or prior to March 14, 2015, we will refund registration costs less \$25 administrative fee. Due to the contractual agreements for food, beverage and material costs, cancellations postmarked between March 15 and April 11, 2015 may be refunded up to 50% of the registration fees. We may be unable to make refunds after April 11, 2015. We will gladly transfer your registration to another person (scholarship) or credit it as a donation.

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