#healourskin
TAKES NYC
more on p. 4

WHEN A PATIENT BECOMES
A CAREGIVER
more on p. 7

A TRIBUTE
TO SIRI
more on p. 16
Summer’s here and with the warm weather comes good news! A generous member of our community has issued a challenge: they will match all “new” dollars 100% up to $100,000! If you haven’t donated to the IPPF before, now is a great time to double the impact of your gift. If you donated in 2014, your 2015 gift needs to exceed that amount and the difference will be matched. If you donated this year before April 24, 2015, any additional gift you make should qualify for the match.

Read more at pemphig.us/100kchallenge_rules. You can contact Monique Rivera at (855) 4PEMPHIGUS (855.473.6744) or monique@pemphigus.org and she will be glad to assist you.

The Patient Conference in New York was a resounding success! I want to thank Dr. Annette Czernik from Mount Sinai for hosting our event. The weekend was a great time – from Friday night at Yankee Stadium sponsored by Biofusion, to Saturday’s lectures and workshops, to Sunday’s panel discussions, this was the most patient-focused conference to date. An astounding 97% of attendees said they would share conference information with their physician, and 95% said the information will improve their quality of life. Read more about this fantastic event starting on page 4, see the pictures on pages 10-11, and if you who missed the Yankees-Mets game, you can read about it on page 12.

The Awareness Campaign is making HUGE strides towards increasing P/P awareness and reducing diagnostic delays. Meet two of our Patient Educators on page 6. Dr. Terry Wolinsky McDonald has tips to keep in mind when a patient becomes the caregiver (p. 7). Michelle Atallah explains desmogleins and the role they play in P/P (p. 8). IPPF founder Janet Segall reminisces and honors the passing of our friend and P/P advocate, Siri Lowe (p. 9).

Tammy, a pemphigus vegetans patient, says the day she was diagnosed was the happiest day in her life. Find out why on page 13. Dr. Ani Sinha has collected blood samples for many years. Learn how this advances research (p. 14). If you have a P/P friendly recipe, Daphna Smolka is putting together a Cookbook (p. 16).

Make twice the impact!

Donate today and all eligible “new” money will be matched 100%.

Find out more or donate at www.pemphigus.org/100kchallenge

In closing, I would like to thank my friend and colleague, IPPF President Dr. Badri Rengarajan, for his years of dedication to the IPPF. After seven impactful years, Dr. Rengarajan is stepping down from the IPPF Board of Directors (see p. 5). In keeping with his goal to increase community engagement, he will continue to support the Foundation as a volunteer.

On behalf of the staff, coaches, medical advisors, and Board members: Badri, thank you for leading the IPPF to a new heights and positioning us for the future.

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

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!

Quarterly related: editor@pemphigus.org
Foundation related: info@pemphigus.org
Letters to the Editor: editor@pemphigus.org
Disease, Treatment, Lifestyle: phc@pemphigus.org

www.pemphigus.org
In April, 150 attendees gathered in the Big Apple for the 17th annual IPPF Patient Conference. Patients, caregivers, loved ones, physicians, and IPPF affiliated members gathered in the Davis Auditorium at Mount Sinai Hospital to hear pemphigus and pemphigoid (P/P) specialists from all over the country speak.

Annette Czernik, MD, Conference Co-Chair and Mount Sinai Hospital assistant professor and dermatologist, along with IPPF CEO Will Zrnchik, kicked off the conference with an exciting overview of the weekend’s events. The conference included guest presentations by scientists and clinicians; a speaker panel with a lively Q&A; a panel of patients at different stages of disease; 11 workshops on topics such as nutrition, oral care, and dealing with stress; and special guest talks by Mark Lebwohl, MD, professor and dermatologist at Mount Sinai and current president of the American Academy of Dermatology, as well as New York Congressman Charles Rangel.

IPPF Board President Badri Rengarajan, MD, provided attendees with an IPPF update. Dr. Rengarajan introduced staff and fellow board members. He also discussed plans for the coming year regarding Peer Health Coaches, Patient Education calls, clinical trials, fundraising, and further advances with the Awareness Campaign. Later in the day, a panel of the IPPF Board of Directors answered questions about finances, research, and the goals of the Foundation.

Awareness Campaign Manager Kate Frantz spoke about the Campaign’s exciting developments, including the Awareness Ambassador Program, which trains volunteers to raise awareness among their local dental community. She highlighted the role that Patient Educators have played this past year in anticipation of the coming year's plan to visit 19 dental schools to educate dental students and faculty about P/P. Kate also shared the recently developed Awareness Campaign website, brochures, and videos.

The conference then segued into introductions of P/P. Dr. Czernik gave an in-depth look at pemphigus while thoroughly explaining the basics of the disease. Jacob Levitt, MD, and Mount Sinai associate professor and dermatologist, took his turn at the podium to explain the essentials of pemphigoid. These talks have been favorites at past...
Dear IPPF community:

After seven years on the IPPF Board of Directors with two and a half years in the role of president, it will be time for me to step down this summer. I am very pleased with how the Foundation has grown and improved in the last two and a half years. We have improved our finances, tightened operations, and introduced new programs and initiatives. The latter includes, among others, launching an awareness campaign, establishing interactions and programs with biopharmaceutical companies, creating a multitiered volunteer program, and establishing an endowment fund. The Foundation is in a better position now than when I took on the role of president.

As I have done several times in the last few years, I once again want to encourage members of our community to get involved in Foundation activities. Your expertise, time, and professional and personal networks will enable the Foundation to better serve our patients. We can create roles with responsibilities and time commitments that fit each individual’s interests, capabilities, and time constraints. Volunteering is a great way for new patients to accelerate their learning and be in a better position to take charge of their lives. It is also a great way for patients in remission to serve as models for our new patients. Please contact the Foundation and explore how you can contribute. Please do get involved.

I want to thank my Board colleagues, medical advisors, and CEO and staff. It has been a pleasure to work with you in advancing the Foundation. I want to also thank our patients and caregivers. Your courage and persistence are inspiring. It has been an honor to work with you.

I will still be involved with the Foundation in a volunteer capacity, likely in the area of research and development, a topic of great interest to me. I look forward to watching the IPPF continue on its upward trajectory.

Best wishes to everyone.

Best,

Badri
Meet the IPPF Patient Educators

Becky Strong & Hannah Heinzig

Patrick Dunn

With the goal of reducing pemphigus and pemphigoid diagnostic delays, the IPPF Awareness Campaign focuses its outreach efforts on specific areas of the dental community. Patient educators provide direct emotional appeals to students and faculty at some of the top dental schools in the United States. Since March 2014, patient educators have delivered 10 presentations at seven different schools, allowing them to reach over 900 students, faculty, and staff. With more guest lectures scheduled into 2016, the program is already an important part of achieving the Awareness Campaign’s goals.

Much of the early success of this program is due to the Patient Educators themselves: Becky Strong and Hannah Heinzig. Both nurses living with pemphigus vulgaris, Becky and Hannah are able to bridge the gap between educational knowledge of P/P and the personal connection of a patient’s experience.

The origin of the Patient Educator Program can be traced back to the 2010 IPPF Patient Conference in Philadelphia. Becky, whose search for a correct diagnosis spanned 17 months, five physicians, and several rounds of incorrect treatments, attended the conference as a newly diagnosed patient. She left inspired by Dr. David Sirois, who told patients that they had the opportunity to educate doctors. At her next appointment at the University of Michigan Department of Oral & Maxillofacial Surgery, Becky and her dentist discussed the idea of speaking to dental students about PV from a patient’s perspective. This discussion led to an invitation to speak to over 200 students at the University of Michigan. Becky wrote about her experience for the IPPF Quarterly, and the Patient Educator Program grew from there.

Hannah’s diagnosis journey included nine...
We all know how much we want to be independent and strong for ourselves. We also know we sometimes need help and how hard it is to ask for it. We don’t want others to think we are weak or lazy. In this column, I have previously addressed issues such as taking care of caregivers and caregiver burnout. What happens when we—the patients—become the caregivers?

Given the nature of autoimmune diseases like pemphigus and pemphigoid, many patients go on to get diagnosed with additional illnesses, both chronic and acute. In addition, we are still susceptible to all the illnesses (cancers, heart disease, etc.) that others can get. Sometimes the very people we depend on to make our lives less challenging become ill themselves. It happens. When the tables get turned in this way, we either take care of each other or the roles may totally reverse, with the patient becoming the caregiver.

Psychologically, doing positive things for others is very important to our own sense of self. We naturally need to feel needed: it makes us feel good to be giving back. But for those of us who have been on the receiving end of someone else’s care, it is critical to understand our individual limitations and not to overtax ourselves. Stress is a significant risk factor for flares, and its management is an important component in maintaining a healthy mind-body connection. If we are unable to take care of ourselves first and foremost, we can not be there to take care of others as well as we may desire.

This can be the really tricky part: how do we know how much more we can handle? We may look well, but not be fully capable of supporting another ill person. I can guarantee
It is widely known that the main players in pemphigus vulgaris (PV) are the desmoglein family of proteins. Desmogleins (Dsgs) are the main components of the desmosomes, which are structures that maintain adhesion among the layers of the skin. Patients with pemphigus produce antibodies against various members of the desmoglein family of proteins. Because different desmogleins are expressed in different parts of the body, the type of antibody a patient has determines which areas are disrupted, and therefore defines the clinical characteristics of their disease.

For example, Dsg3 is strongly expressed in the mucosal epithelium, while the skin has significant levels of both Dsg3 and Dsg1 (this fortuitously allows one Dsg to “cover” or compensate for loss of the other in the skin if an antibody against one of them is present). A patient with antibodies against only Dsg3 is therefore more likely to experience mucosal lesions, while a patient with antibodies against both Dsg3 and Dsg1 is likely to see both mucosal and skin lesions.

While the presence of specific anti-Dsg antibodies can often predict clinical symptoms, there are exceptions to the rule. In a recent article published in the Journal of Dermatology, a group of researchers from Tokyo examined the sera (portion of the blood containing antibodies) from three patients with cutaneous pemphigus vulgaris (cPV), a subset of PV in which antibodies against both Dsg1 and Dsg3 are present, but there are no mucosal lesions (Journal of Dermatology, http://onlinelibrary.wiley.com/doi/10.1111/1346-8138.12888/full). They found that each of these patients produced anti-Dsg3 antibodies, yet none of them had the predicted mucosal lesions. In order to better understand the mechanisms of the disease, they took a closer look at exactly what and how the antibodies were binding.

To determine what the antibodies were binding to, the researchers used a method called immunoprecipitation. Serum from the patients was allowed to mix with proteins engineered to resemble human Dsg3 and Dsg2 (both proteins from the desmoglein family), and the antibodies and the proteins they bound to were pulled out of solution. A dissociation experiment was then used to examine the ability of the Dsg3- and Dsg2-specific antibodies to cause disruption of a sheet of epithelial cells, simulating the disruption to the skin layers that these autoantibodies would cause in a patient. As a comparison, serum from patients whose pemphigus did produce mucosal lesions (mPV) was used as a control.

The researchers found that each patient had a unique antibody profile. All antibodies reacted against Dsg3, but the cPV patients’ antibodies bound to different parts of the Dsg3 protein. The dissociation experiments produced differential results as well: cPV serum caused less damage to the epithelial sheet than mPV serum did, which corresponds with the clinical obser-
In 1998 or 1999, I got an email from a woman in England named Siri Lowe. Siri had been diagnosed with PV in 1995 (and was now in remission?) and wanted to find out how she could best help patients in the United Kingdom with PV. She started an organization in the UK called The PV Network.

In 2000, Siri asked me if I could come to London to meet with her and the top dermatologist working on pemphigus at the time, Dr. Martin Black. Siri felt that a visit from someone at the IPPF (at the time named the National Pemphigus Foundation, or NPF) would bring legitimacy to her venture. I traveled to London, and Siri and I met with Dr. Black. We subsequently also met with other patients with pemphigus and pemphigoid. Although the name of her organization was The PV Network, she often helped patients with pemphigoid as well. My visit and the meetings with Dr. Black and other patients were the first major steps for Siri as a representative for patients living with PV.

Siri’s interests extended not only to helping patients, but also to bringing awareness of the disease to the UK’s National Health Service. She worked with two organizations, the Skin Care Campaign and the Long-Term Medical Conditions Alliance, on a regular basis. Some of the issues she worked on with these groups were to keep dermatology services within the hospital settings. She had told me that the UK wanted to cut back on dermatological services and she had to fight for that not to happen. Siri even was invited to speak to Parliament, which she did.

Siri was not only the head of The PV Network, but she also was my friend. She could be a pretty tough cookie, but she had a very big heart and we clicked right away. We had a lot of similar interests and a lot in common. Whenever I went to London, we always took time together for fun and cultural excursions. On my last visit there, she gave my daughter her one and only ticket to an opera. Although we did not have the love for opera in common, my daughter was excited to see a performance at the famed London Opera House.

In 2001, Siri contacted me to tell me she had been diagnosed with breast cancer. She had a mastectomy and reconstruction. It seemed like her recovery was permanent, but several years later, in 2006,
conferences, and the IPPF couldn’t have asked for more knowledgeable dermatologists to explain the “101” about the diseases.

Sergei Grando, MD, PhD, IPPF Conference Committee member, and University of California Irvine professor and dermatologist, led a discussion on “Challenging Conventional Treatments.” Dr. Grando is a great friend to the IPPF and works with many P/P patients each year. He presented his thoughts on the ins-and-outs of steroids, immunosuppressants, Rituxan® (rituximab), and IVIG (intravenous immunoglobulin therapy), then focused on IVIG. Dr. Grando has immense experience in treating P/P patients with IVIG. He has seen many patients go into remission after using this treatment.

Rituximab is currently one of the most popular treatments among P/P patients, and there is always lively discussion at the patient conference of its use in treatment. Grant Anhalt, MD, professor and dermatologist at John Hopkins University, discussed the various protocols that can be used for P/P patients with this treatment, what patients can expect from it, the side effects they may experience, and more.

Neil Korman, MD, PhD, director of the Clinical Trials Unit of University Hospitals Case Medical Center and professor of dermatology at Case Western Reserve University School of Medicine, delivered three talks over the weekend. Dr. Korman’s first talk focused on emerging treatments and clinical trials. He guided the audience through current clinical trials that various pharmaceutical companies are administering. He explained which treatments are being tested, how they work, how they differ from current treatments, and what can be expected from the treatments and trials. Later, he went into greater detail about how clinical trials are administered, how the protocols are developed, and how recruitment is done.

At the Foundation, we work extensively with Animesh Sinha, MD, PhD, professor and dermatologist at the University at Buffalo. At each conference, Dr. Sinha and his team set up a blood draw station to collect blood samples for patients and their relatives for testing. Dr. Sinha took his turn at the podium to encourage audience members to donate blood to further his lab’s research on identifying genetic markers of P/P. Dr. Sinha also presented his team’s discovery of the HLA
gene associated with PV. He explained the difficulties of determining the causes of P/P and finding proper treatments. You can read more about his group’s published findings in the Spring 2015 Quarterly “Research Highlights” column.

We also convened a panel consisting of Drs. Czernik, Grando, and Anhalt, which allowed conference attendees to ask a variety of questions.

The IPPF often focuses on patients, but we also understand the importance of caregiving and how caregivers need to be taken care of as well. Sheila Warnock, founder and president of SharetheCaregiving, Inc., discussed the importance of taking time for oneself, asking for help when one needs it, and other caregiver needs. She reminded the caregivers in the room how challenging their jobs can be at times, and that it is okay to struggle, but they should always make their own needs as much a priority as those of the patient.

Congressman Rangel gave a compelling speech on the importance of having a voice in politics and advocating for what you want and need. He encouraged the audience to fight for their rights and to be aware of the effect that Congress has on their health. He shared that change is created when individuals advocate for legislation that affects access to care and treatment. This extremely important to rare disease patients.

One of our most dedicated patient advocates at the IPPF is Marc Yale. He took the stage to motivate patients to be their own advocates. Marc gave examples of how advocacy can make a difference in patients’ health, especially when dealing with a rare disease, and how this will make a huge impact on future patients. Marc was empowering. Along with Hannah Heinzig, Carlos Campo, and Bryon Scott, Marc later shared his experiences of empowerment through advocacy. The Awareness Campaign team members each shared their journeys with P/P and how they have empowered themselves through raising awareness.

Dinesh Patel of BioFusion gave a presentation on navigating reimbursement for IVIG.

One of the most compelling discussions at the conference was a unique dialogue between Dr. Czernik and PV patient Esther Nelson. Dr. Czernik asked Esther questions about her PV, how she felt, what the diagnostic process was
like, receiving treatments, and living with the disease. Esther very honestly and bravely shared her roller coaster of experiences in dealing with PV.

Finally, there was a very touching and powerful panel discussion during which a PV patient and board member, along with his father, mother, and sister, shared his story of diagnosis, severe disease activity, and travels to Maryland to see Dr. Anhalt for treatment.

To view presentations from the conference please go to pemphigus.org/get-involved/patient-conferences-annual-meetings/.

The 2016 Conference date and location have yet to be determined, but will be made available soon.

Take Me Out to the Ball Game

Noelle Madsen

New York City . . . home to Broadway, the Empire State Building, the Statue of Liberty, and the New York Yankees. The Yankees have been a talisman to the city since the early 1900s, so when the IPPF was thinking of ideas for a reception venue for the 2015 Patient Conference, we couldn’t have imagined a more perfect place than Yankee Stadium.

The really perfect part? They were playing the New York Mets the same weekend as our Patient Conference. The “Subway Series” is a long-standing tradition between the New York baseball teams. It is a special time when interleague teams get a chance to play each other. It was even more special that the IPPF was able to bring its conference attendees to see the magic happen!

It was an unusually brisk April evening as IPPF staff and conference attendees headed out to Yankee Stadium in shuttles provided by our host venue, Mount Sinai Hospital. There, everyone was welcomed into a special area in the stadium where a huge spread of food and beverages was served. Guests received special gift bags from BioFusion (one of our conference sponsors), the traditional navy blue Yankee baseball cap provided by the Yankees, and the #healourskin sunglasses provided by the IPPF. For two hours, patients and families got to meet one another, as well as speak with IPPF staff, Board of Directors members, exhibitors, and physicians.

After the fun at the reception, all 150 attendees took their seats behind center field. The whole crew had a perfect view of the field as we watched the Yankees beat the Mets 6 to 1. We couldn’t have asked for a better event to start off our annual Patient Conference, although warmer weather would have been great!

The IPPF wants to give a special thank you to BioFusion for making the reception at Yankee Stadium possible. Without their help and support this fun event would not have been possible. Thank you, BioFusion!

Noelle Madsen is the IPPF Patient Services Coordinator and lives in Sacramento, CA. She is dedicated to providing support and education to those affected by P/P. She is a regular contributor to the Quarterly and can be reached at noelle@pemphigus.org
One Woman’s Story:
Pemphigus Vegetans

Tammy

My name is Tammy, and I have pemphigus vegetans, a form of pemphigus that creates lumps or nodules from the blisters. I’m happy to be able to share my story so that others can find comfort with their own diagnoses.

In September 2011, I noticed I had a sore in my mouth. I dismissed it as a canker sore, but more appeared. I also noticed that before the blister formed, I would get a tingling sensation in that spot.

I went to my doctor. He said that I was probably under stress and wrote a prescription for Xanax. Not too long after all this, I noticed that I had a bump on my inner thigh that itched and looked funny. I went back to my doctor, who did a biopsy. It came back as a dermatological issue, and I was referred to a dermatologist. This bump continued to grow, and others appeared, too. What in the heck were these things?

By the time of my first appointment with the dermatologist, these bumps had grown to five times the size that they were when I noticed the first one. He also did a biopsy. He said he believed it was Halogenoderma and prescribed an antiviral medicine and a steroid mouth wash. I tried those for about a week, but the blisters and bumps kept coming. Now they were appearing on my back, head, and torso. I was scared.

I went back to my general physician and was referred to another dermatologist. At this point, my mouth was full of sores. My body was full of blisters, sores, and lumps. My thought when I walked through his door was that one of two things would happen. First, if this doctor didn’t know what this was, I was going to the hospital (and I was completely prepared to be put in isolation until they could figure it out). Second, this was going to kill me. I was getting weak from not being able to eat, and exhausted from the stress of worrying what was taking over my body. I didn’t have high hopes that this doctor was going to know any more than anyone else.

Thankfully, I was completely wrong. He walked in, asked me stick out my tongue, looked at my back, and said, “Honey, I think you have pemphigus, but I won’t know until we do a wedge biopsy and blood work.” This seemed like a brilliant idea to me, and I wondered why no one else had done blood work to see what was going on. To this day I can’t explain to you why I believed him but I did, heart and soul. I knew this man knew what was wrong with me. Steroids were the immediate answer to get this disease to stop attacking my body. I began taking 80 mg of Prednisone a day.

The day of my diagnosis was February 16, 2012, and it was one of the happiest days of my life.

The day of my diagnosis was February 16, 2012, and it was one of the happiest days of my life. I finally felt like I had answers. The steroids worked immediately. By the end of the week, my sores were healing, my mouth was healing, and the lumps were shrinking. My doctor asked me to take part in a study they were doing at Washington University, where doctors and students observed and read
How Can I Help?

Donating Blood for Research

Kristina Seiffert-Sinha, MD

If you have attended the annual IPPF meetings over the past 10-plus years, you have seen us. And even if you tried to avoid us, our team members may have hunted you down. We are the people in the white coats asking for your blood. You may have wondered as you donated, why am I doing this? What will my blood be used for? What happens with my blood and the information I provided after I leave the meeting? And why are these people asking for my relatives’ blood, too?

Why donate?

Despite recent advances in therapy, there is still no cure for pemphigus. All doctors can do for their patients at this point is to keep their immune systems at bay, in some cases more successfully than others. Clearly, more research is needed into the underlying factors of disease development and progression to really understand disease mechanisms and ultimately – hopefully – find a cure for autoimmune blistering conditions.

Our laboratory has been trying to answer questions regarding PV epidemiology, genetics, and immune function for over 15 years, and many of you have already participated in our studies. However, in order to get meaningful results using modern technologies like high-throughput screening assays and next-generation sequencing studies, large numbers of patients and healthy control subjects are needed. As you know by now, you are afflicted with an exceedingly rare condition (it is estimated that there are only thirty to forty thousand cases of pemphigus vulgaris in the United States, compared to 1.25 million Americans living with the autoimmune type of diabetes). That is why it is important for us to enroll as many patients in our studies as we can, both in our own clinics and at the IPPF annual meetings. Also, it is important to follow patients longitudinally (repeatedly over time) to investigate how disease progresses. That is why we will sometimes ask you to donate more than once throughout the course of your condition.

What is my blood used for?

If you decide to participate in our studies, we will ask you to sign a consent form and will typically draw three or four tubes of blood (that is about 20-25 ml, or less than 2 tablespoons). We will also ask you questions about your condition (disease activity, course, treatment) and your own, as well as your family’s, history of autoimmunity. You will be assigned a study identification (ID) number, and your information will be kept strictly confidential. From this point onward, your samples will only be identified by study ID. Your personal data will never be used in

CONTINUED ON NEXT PAGE . . .
any communications and publications unless you instruct us to do so.

We will take your samples to our laboratory where we extract DNA for genetic and genomic studies, RNA for gene expression studies, and serum to analyze your autoantibody profiles. All samples that are not immediately used for our analyses are stored frozen in our large biorepository and can be used in future studies when needed.

While we get some data fairly quickly on your genetic susceptibility and antibody levels, most results are only meaningful if compared to data from many additional patients. It may take years for us to fully complete all follow up studies and to publish the data in the scientific literature. We do hope that, ultimately, our studies will shed some light on why you develop disease and how we can better treat it. We also hope that our scientific colleagues, both present and future, will be able to learn from our findings as much as we learn from theirs.

**Why is it important for my blood relatives to donate blood, too?**

PV is a multifactorial disease with a complex interaction of genes, the immune system, and the environment. While no single factor has been found that will predispose you to develop disease, it is clear that the vast majority of patients carry certain human leukocyte antigen (HLA) alleles, proteins or markers that are found on certain white blood cells that play a key role in immune and autoimmune activation. Interestingly, many family members that have not developed and never will develop disease carry the same HLA risk molecules.

Our group is very interested in exploring how family members who express the pemphigus-associated disease risk alleles (and also family members who do not express these alleles) compare to their relatives who do have the disease. We compare family members using measures such as other genes that may or may not be expressed, autoantibody levels, cytokine levels, and epidemiological data (for example, presence of other autoimmune diseases in the patient’s history). We hope that exploring these additional populations will ultimately help us understand how the immune system protects itself from developing autoimmunity.

**How can I donate?**

Many of you have asked the IPPF how you or your blood relatives can donate. If you are not a patient of our team or cannot meet us at the IPPF Patient Conference, the best way is to get in touch with us via email or phone using the contact information below and indicate the nature of your diagnosis and whether you or your blood relatives would like to donate blood. We will then send you a kit with the required supplies, blood drawing tubes, and instructions. You will need to find a place and a professional for the blood draw. Those of you in the medical field may know a nurse or phlebotomist; others can ask their primary physician to draw the tubes. Once the blood has been drawn, it will need to be sent back to us overnight in our prelabeled, prepaid shipping box (UPS) so that we can store the blood under the proper conditions.

We are grateful for every patient and family member who becomes a participant in our studies. We could not do our work without the commitment and support of people like you!

Kristina Seiffert-Sinha, MD, is a Research Assistant Professor in the Department of Dermatology in the School of Medicine and Biomedical Sciences, University at Buffalo, State University of New York. She can be reached by phone at (716) 842-2118 and by email at krs2002@buffalo.edu.
physicians, three years, and a misdiagnosis of leukemia. A new Patient Educator, she gave her first IPPF-sponsored lecture in March of this year. For Hannah, the lectures have been part of the healing process. “I could not wait to do something bigger than myself and help others in the process,” she said. “[The lectures] helped me to take that first step of the unknown and also regain control and normalcy.”

Becky expressed a similar sense of empowerment: “[It] feels great that little old me has the power to reach so many dentists . . . so I can help somebody else get a diagnosis and get treatment faster than I did.”

As nurses, Becky and Hannah had plenty of experience interacting with both healthcare professionals and the general public prior to becoming Patient Educators; however, addressing large classes of students and faculty was new. Hannah said she was terrified when IPPF Awareness Campaign Manager Kate Frantz asked her to share her story. “I never wanted to be a public speaker, and that is exactly what I am doing. I have to say it has been one of the most rewarding things I have ever done and, believe it or not, very addicting.”

“Speaking in public isn’t always easy,” Becky said, “but it is always worth sharing your story. You never know who you might inspire.”

Both Becky and Hannah have been surprised and encouraged by the emotional response to their presentations. “I was praying that I wouldn’t put them to sleep,” Hannah said. “Instead, I have looked into a room full of compassionate eyes and smiling and tearful faces while pouring out my own story.”

“It’s the emotional way that I tell the story that gets students to connect with me,” Becky said. “Many times, students cry and laugh during my lectures, and many have told my husband how brave we both are for sharing our story.”

The IPPF Awareness Campaign is lucky to have such inspired Patient Educators at the heart of the program. The overwhelmingly positive reactions from both students and faculty underscores the impact patients have in raising awareness about P/P.

“I want to encourage everyone to get involved,” Hannah said. “It truly helps you heal when you help others. It doesn’t have to be big or small. Find what makes you passionate . . . and incorporate it into helping spread awareness.”

Though the Patient Educator Program is one of the “big” ways to get involved, the IPPF also has opportunities that require less of a commitment. The Awareness Ambassador Program trains people to raise awareness in their own communities and can be tailored to fit individual skill sets and comfort levels. More information can be found on the Awareness Campaign website: pemphigus.org/awareness.

---

**Recipe**

Daphna Smolka

- P/P patients know that preparing meals and altering favorite recipes to accommodate dietary needs can be an ongoing labor of love. As part of the goal to provide support and education to those affected by P/P we’re undertaking a fundraising program to create a cookbook.

- So what do we need from you? To start, what we need most are recipes!

Committee Members are also needed for test cooking, data entry, editing, layout, and marketing.

To submit a recipe, go to [www.typensave.com](http://www.typensave.com)

Account #: Smolka

Contributor Password: plate034

Feel free to add in the NOTES section any anecdote or story that goes along with your submission. This will make the final product more personal and memorable.

If you are interested in being a committee member, email cookbook@pemphigus.org.

---

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 patrick@pemphigus.org.
South Florida Support Group

Nancy Corinella, SG Coordinator

On May 17th the South Florida Support Group held their second meeting. We have grown from 5 attendees to 16. Among attendees, we had those who were recently diagnosed as well as those who have had pemphigus for up to 20 years. Everyone introduced themselves and spoke about their journey to proper diagnosis. We are a small community; there were two women who had known each other from a previous support group they had attended in New York, and they now live in the same community here in Florida!

Daphna Smolka spoke about the recent IPPF Conference in New York. She made everyone aware of the matching grant that is going on right now (to the tune of $100,000!) and also touched on the importance of participating in the blood study in progress at the laboratory of Dr. Animesh Sinha [Editor's note: Please see related story, “Donating Blood for Research,” on page 14].

There was such camaraderie in the room. Everyone was sharing information on new treatments and doctors in the area. The meeting was a huge success, and everyone left looking forward to the next meeting. Each and every person felt that they had learned something new, or at the very least made a connection with someone who understood their experiences battling this disease.

DONATE ONLINE AT WWW.PEMPHIGUS.ORG/DONATE

Ippf

patients’ symptoms. My luck had definitely taken a positive turn, as one of the doctors who came in had other pemphigus patients and had previous success putting other patients in remission with Rituxan®.

In April I had my first treatment with a followup in May. I’ve been in remission since. I cannot express my gratitude and happiness that I’m one of the fortunate ones.

I want to share my story because I haven’t met other patients with my variety of this disease. I was embarrassed at first. Blisters and open sores are not attractive. I had a hard time with it. My body healed, but it took a little longer for my mind to heal. I’m no longer embarrassed. Yes, I have this, and yes, it’s not attractive, but I’m a stronger person now because of it.

Thank you for letting me share my story. I hope in some strange way that it helps someone else who is going through their journey with this disease.

Tammy lives in St. Louis, MO. She is 49 years old and is thankful every day that after two treatments of Rituxan®, she has been in remission with no outbreaks.

...continued from TAMMY page 13

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.
the cancer reappeared in her other breast. She again had her cancer removed, and again we thought she was clear. Through this whole ordeal she continued as best she could her work on making sure that PV patients were heard and represented in the UK.

Two months ago, I received an email from her saying that her cancer had metastasized, spreading to her brain and lungs. She had decided she was not going to pursue any more treatment. I immediately called her and we talked for a while about her decision not to continue treatment. She sounded resolved, but still hopeful because she told me she had plans with her long time friend and companion, John, to go “on a holiday.” I thought she might be okay. But several weeks after that I received notice that Siri had passed away. It made my heart very sad.

I met her companion John when I was in London, and he was so kind to show me around and educate me on some of the interesting habits of Englishers of long ago. Siri and John were soulmates. They had met in 1972 and stayed together for all these years. At her funeral, John’s eulogy represented the Siri I knew.

“Siri was a beautiful woman. The photographs in this room attest to this. However, physical beauty is transient. Far more significant is the spirit and character of the person that animates the features. Siri had fierce intelligence, great empathic abilities, deep cultural sensibility, and a compassionate, kindly nature. These combined to give her beauty a captivating radiance. The fact that so many of her friends are here today to celebrate her life is a testament to her vitality and good nature, which always left a deep impression on those who met her.

“My task today is to pay tribute to what I believe is the great achievement in Siri’s life, which emerged out of her personal misfortune. She was diagnosed with pemphigus vulgaris in the autumn of 1995. By her determined effort and application, she set up The PV Network, which has served to provide support and information to others suffering from this disease caused by a malfunction of the auto-immune system.”

She will be missed by her friends and by me – a lot!”

Janet Segall is the Founder of the IPPF and worked as the Executive Director until 2008. She is a Certified Hypnotherapist and Health Coach and the founder of Small Steps Counseling Services, a nonprofit organization focusing on alternative therapies for wellness. She can be reached at (916) 420-1928, or at janetsegall@smallstepscounseling.org.

IPPF Cafe Press
Noelle Madsen

#healourskin

Throughout the years, members of the P/P community have requested that the IPPF staff make T-shirts available for them to show support and raise awareness. The IPPF has answered your requests and generated an IPPF CafePress Store!

Last summer, the IPPF held a social media contest asking individuals to submit designs that represented the P/P community. We received many submissions and held a vote on social media in October. After a month of voting, we had our top four designs.

The Beauty is Feeling Comfortable in Your Own Skin and Crossword designs were both created
that most of us tend to take on too much. If you begin to feel drained, you have already crossed the line between healthy and unhealthy.

Personally, I have a number of diagnosed disorders, but unless someone knows me very well (or has access to my medical records) they are clueless. I don’t look sick. That is fine; I do not want to look sick. However, I make sure to be in touch with my body and my own limitations on a daily basis. This has been put to the test on numerous occasions over the years, but never as much as recently. I am an expert on this as far as my patients are concerned, so it would seem that I should know better. I have always been content to be a strong person, serving as someone who has the knowledge to help others. However, recently I have found greater need to practice mindfulness exercises and to give myself permission to take “pauses.”

What do I mean by “pauses?” Some highly trained people are able to do self-hypnosis and induce trances. More commonly, people practice mindfulness and meditation. Mindfulness has become trendy, and research is starting to support the positive aspects and outcomes of it. To start, you need to sit quietly and intentionally focus on retraining the mind be totally in the present. In practice, this means being focused on your breathing and on your physical state throughout the body.

When you feel yourself getting lost in your thoughts, refocus on the breath, counting how long the breath lasts and the feeling of your body as you breathe. Closing your eyes can help. Consider these pauses, lasting from between 5 and 15 minutes when you first start a daily practice, as a “reboot” of your mind and body.

As you practice, trust that you will come to know your strengths and your limitations. If you find yourself needing to care for another person, you will find it useful to have the skills to listen to your own body and to be the best you can be for yourself and those who need you.

by PV patient Sarah Ricker. The Sunglasses design was created by PV caregiver Sheila Doyle, and the Around the World design was created by PV patient and Peer Health Coach Mei Ling Moore.

The IPPF CafePress store has a variety of products to choose from with each logo: shirts, sweatshirts, jewelry, bags, drinkware, and quite a bit more.

There are three main reasons why we ask you to shop at the IPPF CafePress store. First, when you use or wear these products, you raise P/P awareness. Second, you support the P/P community by purchasing items designed by others affected by P/P. Third, the IPPF receives 20 percent of the proceeds from each purchase.

Check out the IPPF web store for you and your loved ones at www.cafepress.com/ippf. There are always several holidays and other special days right around the corner.