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Message from the Executive Director

Welcome to the Summer 2017 edition of the Quarterly. I’m proud to announce that this is the largest edition the IPPF has ever produced! This journal is dedicated to YOU the patient, and highlights some of the programs and services the IPPF provides to improve the quality of life for all people affected by pemphigus and pemphigoid. Please keep the content coming, and let us know what topics you want to see in future editions.

Since our humble beginnings in 1994, the IPPF’s patient-focused programs have continued to grow and improve. When Janet Segall, IPPF Founder, decided that “helping people live with these diseases was the best thing she could do,” the Foundation was born. To accomplish her goal, she started a newsletter, organized a patient conference, helped connect patients with doctors, and much more! After reading Janet’s story in this edition, you will really understand where we have come from and where we are headed.

The IPPF has grown since those early days, but we’ve stayed focused on our mission. To further our outreach, we encourage our community to advocate, get involved, raise awareness, and share their stories—like many of this edition’s contributors. Over the years, we’ve added more services, such as the Peer Health Coach program, the Patient Education Series, and expanded support group networks.

We also continue to hold patient conferences around the country. Speaking of, please join us in celebrating our accomplishments at the 20th Annual IPPF Patient Conference September 15th-17th in Newport Beach, California. The program will be hosted by Dr. Sergei Grando from University of California Irvine, and Dr. Joel Laudenbach from Western University of Health Sciences. This year’s conference will cover topics important to all affected by P/P. We will also have a special performance on Saturday night by the award-winning “Kenny Metcalf as Elton John.” This is a conference you won’t want to miss! Find more info in this issue and at pemphigus.org/newport2017.

From advocacy to scientific innovation, from drug development to physician education, from support groups to the Patient Conference, the IPPF’s programs improve many facets of our patients’ lives. We are here every day to remind you that you are not alone, as well as to provide the support needed to navigate the emotional, physiological, and social aspects of your disease.

Enjoy this edition of the Quarterly, and I look forward to continuing the journey with you!

Marc Yale
IPPF Executive Director

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For me, rare disease awareness came 33 years ago when I was invited to open the Stomatology Center at Baylor College of Dentistry. The purpose of the center was to diagnose and treat rare diseases of the oral soft tissues. In addition, I was to teach periodontics and oral pathology residents how to do so. As our patient population exploded, it became apparent that there were many people living with these unusual diseases and disorders, but only a few dentists who had even seen and recognized any of them. Since this type of training comes with experience, it was very obvious that dental college graduates were rarely exposed to these types of disorders. Thus, there was a world of undiagnosed or poorly diagnosed people and only a few physicians and dentists who knew how to treat them.

The second part of my educational process came when my colleague, Dr. Nancy Burkhart, approached me 20 years ago to discuss the realities of the lack of knowledgeable healthcare providers worldwide who were trained to manage patients with these rare disorders. She wanted us to start a worldwide support group to offer assistance to individuals who had, or thought they might have, the most common of these conditions: oral lichen planus. I immediately realized what a great idea this was, and away we went! We established a support group and began to advertise that we were available to help answer questions from people anywhere in the world. We pledged to try our best to help them find access to someone in their area who could help diagnose their problem and, hopefully, treat it.

I think we had seven participants in the first chat session that we conducted for our support group. I use the term “chat session” very loosely here because we were completely computer bound. We showed a few images and talked a bit about oral lichen planus, then opened the program for questions. As time went on, we began to invite national and international oral medicine/pathology experts to participate with us in these sessions. They were required to be very computer competent because as we typed our response to one question, another three or four came in. We could never answer all of the questions in these sessions, but we did respond to all unanswered questions in the days following each session.

Now times have changed. We are no longer Baylor College of Dentistry, rather we are Texas A&M...
As our patient population exploded, it became apparent that there were many people living with these unusual diseases and disorders, but only a few dentists who had even seen and recognized any of them.

Other chronic systemic diseases may be important, as well as a list of medications—especially those that can cause mouth dryness or thinning of bone. Diabetes is progressively more common in all age groups today. These are factors that patients need to address with their treating dentist, especially dentists who have minimal or no experience in treating patients with autoimmune diseases. I also often recommend that patients discuss their dental needs with their treating health care provider to determine whether there are factors in their autoimmune disease management that can impact their dental treatment. Finally, a second opinion may be beneficial after they've received the proposed treatment plan. To make this worthwhile, patients may need to see someone with additional knowledge about their dental treatment needs: a periodontist for gum disease, a periodontist or oral surgeon if implants are proposed, or a prosthodontist if fixed bridges or full or partial dentures are recommended.

To date, I've been able to respond to all lingering questions participants ask if they're still unsure after the chat session. This is a time-consuming process, but I believe that all of us with experience in managing these diseases should be willing to go the extra mile for these concerned individuals. I also believe that responding to questions from participants is one of the most rewarding things I do in an effort to help people with rare mouth conditions.

Terry Rees, DDS, MSD, serves as Professor, Department of Periodontics and Director of the Stomatology Center, at Texas A&M University College of Dentistry. He is a Diplomate of the American Board of Periodontology and the American Board of Oral Medicine, a Fellow in the American and International Colleges of Dentists, a Fellow in the American Academy of Periodontology, and a member of numerous professional organizations.
A systematic characterization of the mechanisms of pemphigus vulgaris (PV) and pemphigus foliaceus (PF) unravels some of the signaling mechanisms downstream of distinct autoantibodies against cell adhesion molecules—the desmogleins—which ultimately lead to blister formation in patients. Manipulating these signaling pathways may be a promising therapeutic strategy.

Pemphigus and pemphigoid (P/P) are autoimmune conditions characterized by the abnormal production of antibodies against proteins that are responsible for adhesion between cells of the skin and mucous membranes. The antibodies recognize specific proteins called desmoglein 1 (Dsg1) and desmoglein 3 (Dsg3). Normally, these desmogleins that are expressed on the surface of cells form a bridge between cells by interacting with other desmogleins on neighboring cells or to other cell-surface receptors that bind to skeletal structures within cells (the so-called keratin filaments). The autoantibodies disrupt these interactions and ultimately disrupt the cell-cell connections, leading to blister formation.

Scientists from four research institutes in Germany have been actively studying the molecular-level mechanisms that are triggered when autoantibodies bind to Dsg proteins to ultimately lead to loss of the cell-cell interactions. In a recent study, these authors examined these mechanisms downstream of Dsgs, focusing on several known signaling systems, and concluded that these can be either protective or inhibitory towards disease (Walter et al, Scientific Reports, doi 10.1038/s41598-017-03697-7).

The scientists started by extracting autoantibodies from patients with either PV or PF. The patients with PV had either mucosal PV (m-PV), mucocutaneous PV (mc-PV) or atypical cutaneous PV (at-PV). In general, involvement of the mucosal or skin (cutaneous) systems is predictable in PV, knowing the specific autoantibodies produced by these patients: m-PV
patients produce Dsg3 autoantibodies, while mc-PV patients produce both Dsg3 and Dsg1 autoantibodies. This indicates that Dsg3 is expressed and is important for cell-cell adhesion in both the mucosa and in skin, while Dsg1 is only present in skin. at-PV breaks this rule, however, since both types of antibodies are present, but disease is limited to the skin.

Looking at the specific autoantibodies generated by their patients (and found in their blood), the authors indeed found profiles consistent with their disease (that is, Dsg3 antibodies in all three PV conditions, and Dsg1 antibodies in mc-PV, at-PV, and PF). All of the patient samples could induce detachment of keratin filaments (“keratin retraction”) in an experimental model of skin cells (keratinocytes) that form intercellular junctions, closely mimicking the human epidermis of patients. Autoantibodies from all three PV sample types, as well as from PF, altered the distribution of Dsg3 within the keratinocytes and induced activity of a signaling pathway within cells that is characterized by an enzyme called p38MAPK.

The authors studied several other signaling pathways, including activation of additional enzymes, called Erk and Src, and they monitored the influx of calcium ions into cells (a typical readout of several signaling pathways). Their data suggest that p38MAPK and Src can be activated by Dsg3 autoantibodies, while the calcium signaling pathway and Erk activation were activated by Dsg1 autoantibodies. The authors predict that the loss of keratinocyte attachments correlated with p38MAPK and Src pathways are sufficient to cause mucosal PV but not blistering in skin. Therefore, these systems are causative for disease. Curiously, small chemical molecules that are known to inhibit p38MAPK and the calcium signaling pathway could block the effects of the autoantibodies on keratinocyte cell-cell adhesion. These latter results are consistent with previous research studies that have shown modulation of certain signaling events prevents pemphigus skin blistering in animal models of disease.

The current work highlights the direct connection between autoantibody type produced and presentation of m-PV, mc-PV, at-PV, or PF and attributes these links to the differences in signaling patterns generated by the autoantibodies specific to these diseases. As well, it highlights the potential to manipulate these signaling pathways for disease therapy.

Autoantibodies against Dsg1 (anti-Dsg1 IgG antibodies, yellow) are found in mucocutaneous PV as well as in PF, while autoantibodies against Dsg3 (anti-Dsg3 IgG antibodies, teal) are found in both main types (mucosal and mucocutaneous) of PV. Current research supports a theory where the Dsg type being targeted by the autoantibodies dictates whether blisters will develop in the skin or mucosa (or both). In mucosal PV, anti Dsg3 IgG antibodies induce erosions in the oral mucosa (labeled as mucous membrane in the figure), where Dsg3 is the most abundant Dsg type, but fail to induce cutaneous blisters of the skin (labeled as skin/epidermis). Similarly, the anti Dsg1 IgG antibodies in PF induce superficial blisters in the skin but not in the mucous membrane. In the mucocutaneous type of pemphigus vulgaris, both anti Dsg3 and anti Dsg1 IgG antibodies are present, resulting in extensive blisters and erosions of the skin and mucous membranes. Histologically, suprabasilar (in PF) and subcorneal (in PV) blisters with acantholysis are seen in skin biopsies from patients. Figure adapted from Kasperkiewicz et al., Nature Reviews Disease Primers, doi:10.1038/nrdp.2017.26).

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.
When I finally received my own definitive pemphigus vulgaris (PV) diagnosis in November of 2001, I’d already spent nine grueling and painful months seeing multiple specialists (mostly, but not exclusively, dental) and researching possible reasons for my serious oral pathology. In addition to feeling that my immune system had been compromised for more than a year and a half, my mouth felt like it was falling out in clumps of blood and skin. Cancer had already been ruled out multiple times by erroneous biopsy testing, and I had studied case scenarios of all considered possibilities. I wasn’t tech savvy, but I had a basic working knowledge of the internet. Interestingly, my younger son who was in graduate school at the time, found the IPF (known then as the International Pemphigus Foundation) online support group, which was made up solely of patients.

It was a relief to read real-life and real-time comments and experiences from other patients with my ultra-rare disease! I’m a psychologist, and I understand the emotional and intellectual dynamics of connecting with others. This was almost 16 years ago. Janet Segall was available to contact, and she did make herself available (she had also created a Medical Advisory Board). However, other than sporadic support groups run by volunteers and the relatively new annual patient conference, there wasn’t much else—yet.

Through the online support group, I met some of the most amazing people I’ll ever know. Interestingly, one of the first people I met online was from the Netherlands. In 2002 when I visited a friend in a small town in a neighboring country, she traveled by train to meet me. She brought my friend beautiful fresh flowers and brought me pages of research she had collected about pemphigus, a relaxing CD, and a pragmatically easy to eat and swallow nutritional product. Neither of us had ever met anyone else with PV, and we hugged each other for a very long time when we first met. Our instant connection was incredibly powerful, and we both knew this was a forever connection.

In the fall of 2002, I attended my first patient conference in New York City. It wasn’t fancy, but it was amazing to receive information from the presentations and put faces to names and stories. During the meeting, Janet asked if I’d participate on a panel with other patients. This hadn’t been planned or done previously, but it was extremely powerful. It seemed that participants at the conference were on academic emotional...
overload, and asking fellow patients questions wasn’t as intimidating as trying to form a question for experts who were providing very informative, but complicated, medical overviews of our illnesses and of recent research.

Back in 2002, there weren’t coordinated, Foundation-supported educational outreach programs or peer health coaches. At the time, I reached out to local Pittsburgh medical news correspondents and was able to snag an unexpected three-minute slot on the local ABC television news station. Due to anchor interest and disbelief about the illness, the segment lasted longer and became the lead story on the evening news. It was also repeated several times the following Saturday. Although the story didn’t get picked up nationally, it educated local viewers, saved lives, and helped me start a small Pittsburgh support group. It’s a truly remarkable feeling to know that your personal story can help others.

I was initially surprised to learn that the emotional and psychological aspects of dealing with these devastating illnesses haven’t been well addressed historically. I started writing my "Psychologically Speaking" column in this journal about 13 years ago in order to reach an audience that was not being addressed at the time. When I presented my first continuing education for local dentists called, “Pemphigus: What You Don’t Know May Kill Someone,” the audience’s questions made it clear that more education was needed.

I didn’t miss any IPPF conferences for many years, but after eight years (and many symptoms that didn’t fit in with my PV diagnosis), I was diagnosed with another rare autoimmune disease, and then another. I’ve attended many conferences as both a patient and as a provider. The research is very clear now that people with one autoimmune disease are likely to have others—although not my personal unique combinations. The more I know and learn, the more fascinating it all becomes. At the University of Pittsburgh and University of Pittsburgh Medical Center, there is new research being conducted with specific DNA strands. Special individualized treatments are starting to be used in connection with this laboratory work. It’s a medically amazing time for both current and future generations.

It was a relief to read real-life and real-time comments and experiences from other patients with my ultra-rare disease! Since my diagnosis, I’ve served on pemphigus boards and have had the opportunity to travel internationally and meet pemphigus and pemphigoid patients from numerous countries. It’s been an incredibly rewarding experience. Since then, I’ve watched the IPPF grow in leaps and bounds with an online presence, educational outreach programs, and one-on-one coaching. More and more patients and doctors are being reached, a situation that continues to grow. The IPPF Medical Advisory Board was instrumental in standardizing the language used to describe patients' status. Medical research labs are cutting edge, and the IPPF appears to be keeping pace. Having a rare disease isn’t fun, but we’re getting much closer to improved treatments and, perhaps, an eventual cure. And equally important, no one has to fly solo any more. It’s an exciting time. Get involved and stay involved. There’s power in numbers.

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

Read more at pempress.com
Get weekly pemphigus and pemphigoid news online at PemPress, the IPPF’s news site.
As a trained mental health professional with a background in social work and psychotherapy, my life’s work and passion is supporting others as they cope, survive, and thrive when faced with a wide range of challenges. Working in a private practice and a primary care clinic, I work with many individuals through their struggle with mental illness, trauma, grief/loss, relationship difficulties, and, yes, autoimmune diseases. I hear countless stories of the frustrations with the medical system, battles with insurance companies, and all the changes that accompany a chronic illness. I thought I’d heard enough to understand what it was like to live through these challenges until I found myself in that very position. After a grueling eight months of countless unanswered questions, meetings with five different specialists, dozens of blood tests and three biopsies, I finally received a pemphigus vulgaris (PV) diagnosis last fall.

I was a patient for the first time in my adult life, and I was devastated. Why me? Why this? Why now? As difficult as it was to come to terms with a new series of challenges to overcome when I’d planned on doing so many other things at this time in my life, I have my education and training to thank for providing me with the tools to make the journey toward remission more manageable. I’d like to share some lessons I learned as a result of my experience living with PV.

Surrender to what is or risk further suffering

After spending months feeling uneasy and unsure about what was going on with my body, I experienced some relief after finally getting a diagnosis. Sadly, the relief was quickly replaced with panic and dread when my treatment was outlined.

Up until this point I considered myself a healthy person who didn’t need medication. My breaking point came when my dermatologist said, “We’ll be starting you on 60 mg of prednisone.” I supported several individuals who needed prednisone during my career, and was all too familiar with its unpleasant and scary side effects. Now it was my turn to go through it, and I couldn’t believe it. Realizing I needed to take so many awful medications for an unknown amount of time felt surreal. Living with a rare illness, fatal if untreated, also seemed bizarre. Is this my life? Why is this happening to my body? What will my future hold?
While I knew in my mind that fighting my new reality (i.e. the diagnosis, treatment, and uncertainty over outcome) wouldn’t change what was already set in motion, my heart and soul needed time to accept this new and unwanted chapter of my life. As healing of any kind is a nonlinear process, learning how to accept PV as part of me and my future has, and will continue to be, a daily and lifelong practice. Bringing my attention to the present moment with several different mindfulness strategies helps me find a place of surrender at times when I question my experience or try to predict the future. It’s only from a place of acceptance (different from approval) that I can stop fighting what’s happening and refocus on what I can do about it.

The only way out is through

Chronic illness brings about a roller coaster of deeply felt emotions. Anger, frustration, sadness, grief, fear, confusion, despair, or hopelessness—these emotions are common and necessary at times. As a psychotherapist, I teach individuals to make space for all emotions, even those that cause discomfort, hurt, or pain. I also emphasize that emotions are temporary visitors, helping us identify what is important and what we need at a given moment in time. It’s impossible to always be positive, especially when moving through the challenges that often accompany a chronic illness.

Integrating self-validation through journaling has been a helpful daily routine—especially during those grueling months of heartburn, insomnia, indigestion, moon face, joint pain, mood swings, and fatigue. By writing down my worries, hardships, hopes, and successes, I’m able to tune into my emotions, fully feel them, and hear what they have to say.

Journaling has helped me better understand and accept my internal experience and learn more about who I am with a chronic illness. From that place of awareness and being able to identify what I need, there have been many times when I gave myself a permission slip to have an off day, have a good cry, take time away from work, binge-watch Netflix, set a difficult boundary with a loved one, or order takeout. By being fully present with our feelings—instead of pushing them away or being swallowed whole by them—we can practice self-care and self-compassion. We can also summon the courage to reach out to others for the support we need.

The journey is yours, but you can’t do it by yourself

Even though I came across a fair share of people who dismissed my struggle, tried to somehow “fix” it for me, or just felt sorry for me, I also cultivated relationships with others who knew how to be empathic and caring. In our Western culture, we often romanticize being hyper-independent, where asking for help is considered a sign of weakness or inadequacy. Up until getting sick myself, I’d been lucky to be on the giving end of support and knew firsthand how much courage it took to reach out to others. Nobody could feel what I was going through, and that realization was often accompanied by a sense of loneliness. At the same time, I knew I needed to include a select number of individuals to join me on my journey so I could rely on them for strength, encouragement, and hope during moments of fatigue, overwhelm, or defeat. I asked these incredible souls to check in on me to see how I was doing and updated them on my successes and hardships. On the days when I felt joyful about a small or big victory, they were there to celebrate my success. But more importantly, on the days when I felt hopeless and fatigued, they stepped up with validation and hope, reminding me of my strengths and reassuring me that this was not my final destination.

For those who don’t have this kind of support, you are not alone. I highly encourage anyone with a chronic illness to find a trained mental health professional they connect with who can provide a safe, nonjudgmental space where you can talk freely about your experience, learn new strategies, and feel supported. Asking for help is the most courageous thing you can do, and I know my journey with PV would’ve looked a lot different without my “support team.”

Stay in your own lane

In today’s age of information, even a rare disease such as PV has online forums where questions are asked and experience is openly shared. Although I was reassured to hear of others going through similar treatment and curious to learn how they managed, I also knew that despite the same diagnosis and treatment, my body is unique. Hearing others talk about their painful flare-ups and long-term remissions triggered fear and hope and everything in between. As a result, I continue to remind myself daily to stay in my own lane and focus on my own circumstance instead
of comparing myself to others’ experiences. This not only goes for timelines, symptoms, and treatment, but also extends to coping strategies—what works for me may not work for others, and vice versa. What I found helpful was a combination of daily habits that involved: taking time off from work, spending time with my “support team,” meditation, acupuncture and massage treatments, chiropractor adjustments, clean eating, journaling, exercise, knitting, watching comedies, listening to empowering music, and repeating a mantra when overwhelmed. (“Every day and in every way, I’m getting better and better,” and, “My body and mind are in a process of healing,” are still my favorites.) It takes time to figure out what works for you, but I assure you that it’s a worthwhile experiment as these incremental tasks over time made a tremendous difference in my physical and mental health, building resilience to face and survive the darkest of moments.

Life is brutiful (brutal and beautiful), and gratitude comes in ordinary moments

As peers my age became parents and purchased property, I was busy fighting my insurance company to cover rituximab (I lost miserably, even after five appeals). As my friends took selfies in beautiful destinations or of their baby bumps, my photo album consisted mostly of pictures of my mouth/gums and growing moon face. That really sucks and isn’t fair. I didn’t do anything wrong or ask to be sick. But after a decade of supporting others who also didn’t ask for their struggle, I know that life is unfair and awful things happen to people all the time. As much as possible and on most days, I’m able to acknowledge the challenges I’ve been through and that may lie ahead of me, while at the same time also recognizing the small and large things that I’m grateful for. Even on days where I’m frustrated, sad, or scared, I can be grateful for my soothing warm cup of tea, my husband coming with me to my specialist appointment, getting my blood drawn on the first try, a friend sending me an adorable picture of her newborn daughter, hearing my favorite song on the radio, or witnessing a beautiful sunset. Unfair and horrible things can and do happen. But in every difficulty, tragedy, or challenge, there’s a nugget of gratitude. And we need to find it. If we can acknowledge and hold on to that gratitude, it can help us better cope and strengthen our hope for a better tomorrow.

What makes you weak makes you strong

I wish resilience was possible without adversity, but that’s not the case. Through all the difficulties, challenges, and changes that PV has bestowed upon me, it’s also given me gifts of greater self-awareness, an improved ability to connect with others, and a deeper practice of boundaries and self-care that often went unchecked in my role as a helper. Having a chronic illness forced me to reevaluate my priorities and learn (sometimes the hard way) who is really able to be there for me in good times and in bad. But perhaps the greatest lesson this experience has taught me is how resilient I am, even in those vulnerable moments. I am proving to myself how tough I can be, even as I yearn for certainty and wipe tears from my face. Thanks to PV, I’ve overcome countless obstacles and faced so many fears. I know this newfound resilience will serve me well as I continue this journey.

The piece of work that has been transformative to my recovery has been the research of Dr. Brené Brown. Brené is a researcher and professor who has spent over 15 years studying vulnerability, courage, shame, and worthiness. In my private practice, I facilitate The Daring Way™—a psychoeducational workshop she created to help individuals show up, be seen, and live a brave life. I strongly recommend reading her books and participating in The Daring Way™ workshop. Putting her research to practice has helped me cultivate the compassion, connection, and courage required to face, and learn how to coexist with, a potentially fatal disease that (as of yet) has no cure. If you’re reading this and are doing well, take a moment to acknowledge how far you’ve come and express gratitude for where you are today. If you’re reading this and are in the midst of your struggle, take a deep breath and know you are not alone. Acknowledge this is where you are today and try to do one small thing to care for yourself with the hope that better days are ahead. As both a mental health professional and a patient, I know they are.

Ivana Mitchell is a Registered Social Worker, Psychotherapist, and Certified Daring Way Facilitator, living in Toronto, Canada. She provides psychotherapy in a primary care clinic and private practice, as well as facilitates Brené Brown’s psychoeducational workshop The Daring Way™, created to support individuals show up, be seen, and live braver lives.
THE YEAR SO FAR
IPPF Patient Services, Jan-Jul 2017

Patient Education Series

- 6 patient education calls
- 590 registered participants
- 255 downloaded calls

621 New Patient/Caregiver Cases

99% Overall satisfaction rate!

Regional Support Group Meetings

11 meetings
- Mid Atlantic
- South Florida
- Southern California
- Tri-State (NY/NJ/CT)
- Boston, MA
- Buffalo, NY
- Austin, TX
- Houston, TX

133 attendees
If you’ve ever been to Manhattan’s Times Square during the week, you know what it feels like to be surrounded by thousands of people. I’ve often found myself there on business, and it’s a strange feeling to be among so many people and yet feel completely alone. That’s kind of what being diagnosed with a rare disease feels like.

On April 1 of this year, a small group of people gathered in Buffalo, NY, for our first pemphigus and pemphigoid (P/P) support group meeting. As the organizer, I was aware that the first meeting might have limited attendance. I was pleased that three patients, two support guests, two presenters (Dr. Kristina Seiffert-Sinha and Dr. Thomas Chu), and Karen Easton of NuFactor (meeting sponsor) attended.

The meeting opened with introductions followed by an informative presentation by Dr. Seiffert-Sinha on the difference between pemphigus vulgaris (PV) and pemphigus foliaceus (PF). Dr. Seiffert-Sinha is a Research Assistant Professor of Dermatology at the University at Buffalo (SUNY). She provided great insight on the actual diseases, but even more interesting was the conversation about how or why certain people develop autoimmune conditions.

Dr. Seiffert-Sinha and Dr. Animesh Sinha (who was unable to attend the meeting) are leading research doctors in the P/P field. They’ve made great strides connecting the genetic link in PV. Dr. Sinha discovered that 95 percent of North American patients with PV express either HLA DRB1*0402 or HLA DQB1*0503 (genetic markers) in their DNA. The other components beyond DNA are environmental factors and immune regulation issues. Some of the environmental factors that can over stimulate and engage full autoimmune activity include drugs (medicine), food triggers, pesticides, and stress.

Dr. Thomas Chu, a dermatologist practicing at the University at Buffalo, spoke about the current drug trials for both PV and PF patients. Dr. Chu has a personal interest in researching hair loss issues, which all three of the patient-attendees have dealt with or are experiencing. This became an emotional and key part of our conversation.

Near the end of the meeting I was asked by one of the attendees why I took the lead on organizing a regional support group. I didn’t have a solid answer at the time other than knowing it would be good for everyone involved. Personally, I had been so longing to meet...
others dealing with this disease that I almost drove six hours to Virginia to attend a three-hour meeting there.

I am completely on my own without family, kids, or a spouse, and my extended family lives over 1,000 miles away. Although I have a tremendous support group of friends in the Buffalo area, it’s hard for them to wrap their minds around what I’ve faced and what I continue to deal with on a daily basis. Emotionally, they can only support me to a certain extent, and although participating in Facebook groups can be helpful, I know that being in touch with other patients within driving distance is beneficial.

If you look up the side effects of prednisone, “a false sense of well-being” is listed. A false sense of well-being is a side effect? The thing is, yes, prednisone can mask muscle pain (we may end up feeling it as we taper off), which can cause us to do things like yoga and not realize that we have overstretched or overextended our tolerance levels. I think that a false sense of well-being actually extends to the people around us in our daily lives. When we’re at our worst with P/P we may lose weight, choose not go out due to open lesions, and sometimes our skin is scary to look at. Prednisone, while a miracle drug for us, heals our skin but doesn’t stop the disease. If we aren’t extremely careful it may cause other issues with blood sugar, bone density, sleep, weight, and the list goes on.

The people around us may not see us as “sick” anymore because we may eat foods other than protein shakes and soup, and we may gain weight back (and then some, due to side effects of the medication). Some will advise that we go to bed earlier so that we aren’t so exhausted the next day, not understanding that the drug that keeps our skin on also wakes us up every few hours and physically makes our bodies shake to the point of being unable to hold a cup correctly. I’m confident that most of the people around us don’t understand the fear that creeps up within our hearts when we wake up coughing or when someone sneezes near us. They don’t truly understand what having a compromised immune system means. For us, someone else’s sneeze could easily lead to a round of antibiotics because we developed bronchitis from a chance encounter.

A support group with other people in a similar boat is like having a life vest available—especially when the wind picks up and the waves start to crash onto our lives. Having people who have already weathered some of the storms and others who are just realizing that they are now in this boat adds oars, a rudder, and even a sail that can change the direction for the better. This is why I chose to step into the role of regional organizer.

I have many stories to share, but one time on a business trip in New York City I was on my own walking through Times Square when I heard a voice call out, “Lisa Ann, Lisa Ann from Wisconsin!” I turned and saw a couple waving at me, one of whom was wearing a Packers’ jacket. After acknowledging them with a smile and hello, I found out that the couple was from my hometown. Their son and I had been in the same 4-H group growing up. This moment proved that even in a sea of people you never know when a familiar face will brighten your day.

The Buffalo-area patient support group will meet from 10:00 a.m. to 12:00 p.m. at the Big Tree Wesleyan Church, 4163 Fairview Parkway, Blasdell, New York, on the following dates (please read the description for planned topics).

September 9 - The Medication Labyrinth
A frank conversation with doctors and pharmacists about various commonly used drugs and the preventative measures to offset the long-term side effects many of these drugs can cause (University at Buffalo Dermatology and potentially a panel of additional experts).

November 4 - The Nutritional Element
Environmental factors are acknowledged as having a role in triggering autoimmune diseases. Food is a big part of that. We’ll have a conversation with nutrition experts and doctors about food, supplements, and deciphering the plethora of information found online.

January 13 - Fitness When It Hurts
Fitness has multiple components, including physical strength and mental well-being. We will explore what people are doing to keep their bones and muscles healthy while they battle an autoimmune disease.

Lisa Ann Krutzik is a photographer, writer, entrepreneur, religious education director, and student of the world. PV shifted her perspective onto health and wellness. Find her blog at LARoxLife.wordpress.com.
In May of 2015, I was diagnosed with pemphigus vulgaris (PV). I’d never heard of this disease, and I’ve learned that doctors know very little about it as well. I was quickly bounced around from my family doctor to an oral surgeon, and finally to a dermatologist. This seemed strange to me since my lesions were all internal, but I was assured that a dermatologist was the right doctor for my treatment. Within one week of experiencing my first lesion on my gums, more lesions spread to my entire mouth, sinus cavity, and throat, which took away my ability to eat, drink, and speak.

Desperately looking for answers to help me understand this disease, my wife and I searched the internet and found the International Pemphigus and Pemphigoid Foundation (IPPF). We found Becky Strong’s patient story video on the IPPF website, which was so similar to mine. I have to admit that I was a bit apprehensive at first when we came across this website, but I knew I had to find out all I could about this organization and the disease itself. My wife and I read about their peer health coaches and decided to email Becky to see if we could meet with her. She offered to meet us for coffee while she was in town and we jumped at the opportunity. We set a date and met her and her mother at a local Starbucks. This was our first contact with another PV patient. After finding out she had many of the same experiences I had encountered, it completely put me at ease. Before long we were finishing each other’s sentences like old friends reminiscing. We met at Starbucks as strangers and left as friends with an eternal bond. I realized we weren’t two PV patients; we were two PV survivors exchanging battle stories of our disease sprinkled with a few much-needed laughs. Anyone that has dealt with or knows someone with this disease knows it isn’t a laughing matter, but it’s essential to find positivity within such an unknown disease. What better way to do that than with another patient?

When we first heard about the annual conference from Becky, our curiosity peaked. One week after our meeting, I exchanged emails with a peer health coach, Jack Sherman. Shortly after that I had the opportunity to speak to Jack over the phone. It was in this moment that I began to understand how rare this disease really is. Jack told me about an infusion treatment he’d received called Rituxan. My wife and I wanted to learn more about the treatment options and try to understand this disease better. Speaking to Becky and Jack showed me that there’s light at the end of the tunnel. I realized that I wasn’t alone and that others are willing to share their stories, many like mine.

After learning more about the 2016 Annual Patient Conference in Austin, TX, from Becky and Jack, my wife and I decided we needed to go. We didn’t really know what to expect when we arrived, but couldn’t wait to find out. It was great to finally meet so many individuals we’d spoken to, and we were welcomed...
IPPF Scientific Conference in Lübeck, Germany

The fourth IPPF Scientific Conference was held June 22-23, 2017, in Lübeck Germany. Organized by the IPPF and the University of Lübeck, this conference followed the tradition of bringing together clinical and basic science experts in the field of autoimmune bullous disorders. The clinic at the Department of Dermatology at the University of Lübeck is an international reference center for the diagnostics and therapy of patients with autoimmune diseases. Previous IPPF Scientific Meetings were held in 2001, 2005, and 2010 at the National Institute of Health in Bethesda, MD. This was the first IPPF Scientific Meeting to be held outside of the US.

The conference had over 225 attendees from over 14 different countries. Eighty scientific posters were on display, with 18 of the abstracts being chosen for oral presentation. Conference participants heard about novel insights into the pathogenesis of autoimmune bullous diseases and learned about the most up-to-date diagnostic and therapeutic approaches for pemphigus and pemphigoid. Hosts Detlef Zilikens, MD, and Sergei Grando, MD, engaged the scientific community with diverse topics related to both disease. These included genetics, clinical presentation, immunopathology, and treatments.

The 2017 IPPF Scientific Conference was a huge success and helped identify research opportunities that will promote understanding of the causes of pemphigus and pemphigoid, as well as provide experimental and clinical justification for novel treatment options. This meeting will have a dramatic impact on the development of coordinated international efforts to study pemphigus and pemphigoid. In response, the University of Lübeck has already invited the IPPF back again for our next Scientific Conference!

April 2017 was a turning point for me. I started the rituximab and IVIG infusions we learned about at the conference in hopes of remission. To this day, I’ve been able to drop my prednisone dosage in half and am continuing to drop weekly until—hopefully—I’m free of needing it anymore. Contacting the IPPF was the best decision I made, and we’re thankful every day that we took the chance on attending the patient conference. The conference gave my entire family hope, and for that we are eternally grateful.

Tony Golda is a PV patient and is a lead cook for Brookdale Senior Living. He was diagnosed in 2015 and is currently undergoing intravenous treatments of rituximab and IVIg. Susie Golda is an office manager for an Illinois land surveying company and is an animal ambassador with their therapy dog. The Goldas live in Illinois with their two children and the family Goldendoodle.
When you feel like you’re striking out, know that the IPPF Peer Health Coaches are on your team. Our coaches are ready to help you square off against pemphigus and pemphigoid (P/P) and turn life’s curve ball into a home run!

The IPPF Peer Health Program started after Marc Yale was diagnosed with mucous membrane pemphigoid in 2007. Marc wondered what he could do to help others diagnosed with P/P and became active in the IPPF through the community website. As he learned more about these diseases, he started to educate others. Soon, he was offered the chance to become a certified Peer Health Coach (PHC) for the IPPF.

As the community grew, so did the number of people reaching out for help. The need for more PHCs became evident. People reached out to the Foundation to improve their understanding of P/P, learn more about treatments, and find information on effectively communicating with their doctors. The Peer Health Coach program gave people just what they needed: the opportunity to share their experiences with, and learn from, an experienced patient.

PHCs are the ultimate utility players on a P/P patient’s team. This year alone, our coaches have already helped patients in over 600 situations. They provide hope when all hope seems lost. Each one will offer peer support, help find local doctors, answer treatment and symptom questions, and more. After working with a PHC, one patient stated, “Our spirits have been lifted. This has been a scary journey so far. It is helpful to know we are not traveling alone!” Our coaches want the best for you, and they’re an awesome tool in the arsenal to fight P/P.

“I really appreciate this resource, as consistent and coherent advice from doctors about a complicated, serious condition isn’t always forthcoming. It was also really nice to hear a personal story— it really makes me feel less alone,” said a patient after communicating with a PHC.

Being affected by P/P, we’re automatically a member of a team none of us asked to join, but it’s nice to know we’re all in this together.

Have you thought about calling the IPPF to speak to one of our coaches, but don’t feel comfortable because you don’t know who they are? Let’s introduce you to our line-up and tell you more about each coach.

Becky Strong
Janet is the founder of the IPPF. She was diagnosed in 1983 and started the Foundation in 1994 with the purpose of giving people living with P/P a place to find information and connect with others. Janet graduated with a Bachelor of Science degree in psychology. After college, she worked at the Pilgrim State Mental Institution on Long Island, NY. Upon moving to San Francisco, she volunteered at the San Francisco Mental Health Department assisting a psychiatrist in the psychodrama group. She also worked at the Women’s Refuge in Berkeley, CA. In 2009, Janet received her certification as a hypnotherapist and began working with the IPPF again as a PHC in 2015.

Mei Ling was diagnosed with pemphigus vulgaris (PV) in 2002. She has been a PHC with the IPPF since September 2012. She became a coach because she was very vocal at the San Francisco meeting that year, and the Director of the Foundation asked her if she would participate. Professionally, she has worked in television production, at major talent agencies, for an award-winning architect, and at vet clinics (she loves dogs). Along with Marc Yale, she helps organize the Southern California support group meetings. Mei Ling lives in West Los Angeles.

Jack was diagnosed within a week of going to his dermatologist in 2002. He became a PHC in 2010. Jack has a Bachelor of Arts in education and is now an IT professional. In his past life, Jack had a successful portrait photography studio and was a professional bass player. He lived in the Seattle area up until three years ago when he moved to the Bay Area. Recently, Jack returned to Washington State to live closer to his son.

Becky was diagnosed with PV in 2010 after a 17-month-long journey to find out what was happening to her body. Although it took a while to respond to CellCept® and steroids, Becky achieved remission in 2013. She’s been a Patient Educator with the IPPF Awareness Program since 2014 and became Outreach Manager in 2016. Becky’s kids and husband keep her pretty busy in Michigan, but she loves spending as much time as she can with them. She likes to swim, play the piano, and go for walks with the dog.

Rudy is from the great state of Texas. He was diagnosed in 2009 with pemphigus foliaceus. He likes to hunt and compete in BBQ competitions. Rudy likes the outdoors and has the support of a loving family—his wife Jennifer of 24 years and four children, ranging in age from 5 to 23.
I was diagnosed with pemphigus foliaceus about eight years ago. It’s been a long and stressful journey for me, but I’ve been in remission since November of 2016 without active lesions or disease activity. I’m both a peer health coach for the IPPF and the Austin Support Group leader. I decided to start a support group since there wasn’t a group in the Austin area, and I thought it would be beneficial to patients.

Starting a support group is a lot easier than one might think. Once I decided I was willing to put a group together, I got in touch with Becky Strong at the IPPF. I asked her for additional details and meeting topics. The IPPF provided me with informational brochures, sunglasses, lotions, and other “goodies.”

As for location, there are many different places to hold a meeting. Hotel meeting rooms, restaurants, and public libraries are good options. Some locations will offer a discount or waive the reservation fee if they’re aware the meeting is for a nonprofit. I try to choose a place that has a relaxed atmosphere. I typically reserve the space at least a month in advance so the IPPF can promote the meeting. I also created a Facebook group so patients are able to follow upcoming events.

The group can decide to serve food. I usually serve beverages, sandwiches, fruit, and chips. Setup of the room is simple. I try and encourage a social environment, as opposed to someone standing in front of the group and speaking. We sit at a long table or in a circle so everybody is able to participate.

The meeting topics can vary, and I leave it as an open floor. The group decides what they would like to discuss each meeting. For example, we discuss medication; flare-ups; channeling stress into something more productive; different foods and their effects; weather; heat; and how this disease affects not just us, but also our loved ones. As a support group grows, it’s possible to invite a dermatologist, dentist, or other medical professional as a guest speaker. There isn’t a specific number of guests that need to attend. All that’s needed are two patients willing to share their journeys, and that is a group.

What does the group get out of the meeting? Personally, I get a sense of fulfillment that I’m helping others going through the same feelings that I’ve been through, and that I’m not alone. (My personal motto is that pemphigus “can’t grind me down.”) I hope the other attendees also feel less alone. I hope they feel I’ve answered their questions and they’ve learned something new. Outside the meetings, we keep in touch about our progress throughout this journey. The group feels close, like a family.

Rudy is an IPPF Peer Health Coach and an active part of the IPPF community. He enjoys being outdoors, fishing, camping, and hunting. He cherishes every moment he spends with his family and friends.
District Outreach in Virginia

Carolyn Fota

As a bullous pemphigoid patient, Mid-Atlantic Support Group leader, and volunteer, I recently met with Karen Klotz, Outreach Coordinator for Congressman Rob Wittman (VA), at his district office. It was a pleasure visiting with her and discussing the needs and interests of the pemphigus and pemphigoid (P/P) community as advocated by the International Pemphigus & Pemphigoid Foundation (IPPF). In preparing for the meeting, I used skills that I learned from February’s Rare Disease Week on Capitol Hill and information from the IPPF. I also learned about health policy and legislation that impacts rare diseases.

First, I sketched the basic points that I wanted to convey to Congress Wittman’s staff, which were recognition of previous rare disease support, awareness of rare diseases like P/P, and a request for upcoming legislative support. I researched Rep. Wittman’s legislative record to familiarize myself with his priorities.

Second, I reached out to Becky Strong and Marc Yale at the IPPF and asked for specific rare disease information that I needed. I thought it was important to know how many Virginians live with a rare disease in order to make this personal to Rep. Wittman’s staff. Additionally, I requested information about upcoming legislation of the OPEN ACT (Orphan Products Extensions Now, Accelerating Cures & Treatments). The IPPF’s support was critical to my overall visit in terms of having the correct information.

Prior to the meeting, I wrote and rehearsed a simple script in order to make an effective impact. Here were my main points:

• Thank Rep. Rob Wittman and his staff: They have supported the Rare Disease Congressional Caucus.
• Ask for support of medical research, funding, and awareness of P/P and other rare diseases: Virginia has over 7,000 people who live with a rare disease.
• Ask for support of the OPEN ACT: This could bring hundreds of safe, effective, and affordable medicines to rare disease patients within the next several years by incentivizing drug makers to repurpose therapies for the treatment of life-threatening rare diseases and pediatric cancers. The OPEN ACT could allow for insurance reimbursement of otherwise off-label treatments or procedures, and reduce the cost of orphan therapies.
• Ask for support of rare diseases like P/P: I made sure to share details about P/P and how it impacts the lives and families of our community in terms of pain, delayed diagnosis, treatment, cost, insurance complications, and isolation.
• Bring P/P to Capitol Hill: Tell our story!

I arrived early and brought IPPF brochures, a handout about the OPEN ACT, #healourskin sunglasses, and a small bag of healthy goodies. I dressed in corporate black and entered the room with a smile, thanking everyone for their time. The visit turned into a 45-minute meeting filled with back-and-forth discussion, questions, and a promise to send my packet to Rep. Wittman’s office in DC. Rep. Wittman’s staff was professional and caring. I was impressed! I followed up the visit with a professional thank you email to Rep. Wittman’s staff.

Throughout this process, I learned more about our nation’s legislative process, the need to advocate for health legislative/policy issues, and that people really do care about the lives of others. The more we bring awareness to rare diseases like P/P, the more that others (and our nation’s leaders) can support us.

Carolyn Fota lives in Stafford, VA, with her husband, Frank, and their three crazy cats. Carolyn enjoys walking, yoga, church, and writing.
I was diagnosed with pemphigus vulgaris (PV) in 1983 at 37 years old. From the beginning, I thought about starting a foundation because I felt very alone. My local doctor, who was terrific, knew about PV, but didn’t know anybody with it. The expert in San Francisco knew some patients, but he said they were older and wouldn’t contact me. So I left it alone. I didn’t have the internet as an option, so all of my information came from the library. Luckily my brother and sister-in-law were librarians and gave me many articles on PV. I learned a lot.

For 10 years, I went in and out of remission. One day, after I came out of my third remission, I decided that it was time to start a foundation. I would start an organization—no one else had. I took it one step at a time. I saw the names of doctors treating and studying PV on the papers I was reading, so I wrote letters looking for support. On some of the letters, I even signed my name “Janet Segall, Ph.D.” so they wouldn’t throw my letters away. After writing several letters, I received a reply from Dr. John Stanley at University of Pennsylvania who said it sounded like a great idea, but he was too busy. He told me to write to Dr. Grant Anhalt at Johns Hopkins. I did, and Dr. Anhalt wrote back saying he was interested. I was so pleased. I bought several books on how to start a nonprofit and followed all the steps. In 1994, the National Pemphigus Vulgaris Foundation was born.

I learned a lot about the disease from my own experience, and I was hopeful I could help others and not feel so alone. Dr. Anhalt sent me his American Academy of Dermatology (AAD) book with a complete list of dermatologists that belonged to the Academy. I typed 1,000 names into a database and sent a letter out with Dr. Anhalt’s signature telling
the doctors about the Foundation and asking them to fill out a survey. I only received 75 responses, but our name was out there. The internet was more common at this time. An online reporter did a story on me, and people started to contact me. I then started a newsletter and put together a medical advisory board.

I needed a focus. I thought about research, but the doctors suggested not to focus on that. Research was about raising money, and that wasn’t anything I was any good at. So, I decided that helping people live with PV was the best thing I could do.

As more people joined, we grew. With the help of several terrific volunteers, our newsletter was becoming a professional magazine. We put together the first annual patient meeting in Chicago. As the years went by, the annual patient meetings improved. More and more people were getting the support they needed.

Because we didn’t have very many staff or volunteers, going beyond giving support and information was difficult. We investigated whether we could set up a fund to help people get to doctors if there wasn’t a doctor in their community, help pay for medication, or expand overseas. Although we couldn’t put together a fund to directly help patients, we expanded overseas.

I was so excited when Siri Lowe, a PV patient in London, contacted me in the late 1990s. She wanted to set up an organization in London. She wanted to operate an organization in London. She wanted to show Dr. Martin Black, a lead P/P dermatologist in England, that she was serious, so she asked me to come to London to meet with them. From there, I made trips to France, Italy, and Israel to help patients set up their own groups. We even had an annual patient meeting in London. It was a great success.

We also focused on physician outreach. We collaborated with the Coalition of Skin Diseases (CSD), the American Autoimmune Related Diseases Association (AARDA), and the National Institutes of Health (NIH). In conjunction with these organizations, we were able to reach out to physicians at AAD meetings and start talking about P/P on Capitol Hill. We were also able to organize and support several physician meetings that focused on research. At these meetings, I wanted to make sure that a short segment was given to a patient in order to add a human touch to the scientific focus.

I was sorry to leave the IPPF in 2008, but in Will Zrnchik’s (former IPPF Executive Director) hands the Foundation grew much more than I could have taken it at the time. He expanded the Foundation by hiring several wonderful, hard working people such as Kate Frantz, Monique Rivera, Patrick Dunn, and Noelle (Madsen) Delaney. Marc Yale also volunteered so much of his time. We were always trying to find a way to bring more awareness to the dental field, and that came to fruition. More support was given to patients, as well as to caregivers (one of my passions).

At these meetings, I wanted to make sure that a short segment was given to a patient in order to add a human touch to the scientific focus.

The IPPF has grown in such a positive way. With a great staff, I see people getting more help, researchers receiving support and making advancements, and doctors becoming more informed. The IPPF’s online presence has also grown exponentially through the website, PemPress, Facebook, and Twitter.

There are a few things that I would still like to see the IPPF accomplish. I’d like to see the IPPF provide funds to patients that are unable to afford rituximab or any new drug options in the future. I’m concerned that the uncertainty surrounding healthcare will make these issues harder to solve. I certainly understand the reasons why it takes so long to approve a drug for a disease, but I think with such a serious illness the process could somehow be sped up.

I’m excited to be working with the IPPF again. I hope to see better drugs available and maybe even a cure in my lifetime. Marc Yale (current IPPF Executive Director) is an amazing leader for this organization, and I cannot wait to see what he will make happen.

Janet Segall is the Founder of the IPPF and worked as the Executive Director until 2008. She is a Certified Hypnotherapist and Health Coach. She can be reached at (916) 420-1928, or at janet@pemphigus.org.
Happy to Help

Becky Strong

It's been a busy year at the IPPF, and we show no signs of slowing down! We’ve had many regional support group meetings across the country. The Patient Education Series has had a call almost every month chock full of great information, and our Peer Health Coaches offer phenomenal one-on-one support to many in our community. We’re also in the final preparations for our annual patient conference in Newport Beach, CA.

Do you know about all the services offered by the IPPF? Here are some updates.

Annual Patient Conference

The annual IPPF patient conferences bring together patients, caregivers, top pemphigus and pemphigoid (P/P) physicians, researchers, and sponsors for an exciting weekend of information exchange and friendship building. Our speakers are internationally recognized for their contributions to the P/P community. Additionally, we invite local dermatologists, dental professionals, immunologists, nurses, and others to provide attendees with direct access to the experts in their community. Each year, the IPPF holds the meeting in a different location around the United States. This year the conference will be held at the Hyatt Regency in Newport Beach, California.

We have two co-hosts for our 2017 meeting, Dr. Sergei Grando and Dr. Joel Laudenbach. Dr. Grando is an immunodermatologist affiliated with UC Irvine Health who specializes in the treatment of P/P. He has more than 225 research papers to his name and has been awarded numerous grants from the National Institute of Health. Dr. Grando sits on the IPPF Medical Advisory Board and has helped spread awareness within the dental community at an IPPF exhibit booth at a recent meeting of the California Dental Association.

Dr. Joel Laudenbach is an assistant professor at the Western University of Health Sciences School of Dental Medicine. He provides educational courses to dental, medical, and healthcare professional societies, study clubs, and postgraduate training programs. Dr. Laudenbach first met Kate Frantz, Awareness Program Manager, at an American Dental Education Association meeting where Kate convinced him to let me visit and speak at his university. He is a member of the IPPF Dental Advisory Committee and will be presenting at the 2018 California Dental Association conference in San Francisco with Marc Yale.

Our generous sponsors help keep attendee registration costs affordable, while providing valuable samples, resources, and information to attendees. This year, attendees will enjoy great educational seminars and breakout sessions, bond with other patients during social times, and even be entertained by PV patient and professional Elton John impersonator Kenny Metcalf!

Support Groups

We’ve added two new support groups to our growing list of regional support led by volunteers. These groups are open to all people affected by P/P. There is something special about being in the same room as somebody else who “just gets it”—who fully understands what it’s like to live day to day with P/P. These groups typically meet in libraries, community centers, churches, and restaurants around the country. Together they are turning a negative situation into a positive experience.

We have support groups in Austin, TX; Boston, MA; Boca Raton, FL; Buffalo, NY; Washington, DC; Houston, TX; New York, NY; and Los Angeles, CA. These groups have become an extension of the IPPF, helping to support P/P patients at the local and personal level.

The Mid Atlantic/DC area support group started in February and is planning their third meeting. The group has found a great mascot, Paz the Dog, and challenges other groups to find mascots of their own! Buffalo/Western NY had their first meeting on April 1, and they too are full steam ahead with planning their third meeting for the fall. Programming topics include mentally coping with pain...
Becky Strong is a PV patient and the IPPF Outreach Manager. She was diagnosed in 2010, but is currently in remission. She lives in Michigan with her husband Tim and her young family.

and research updates. The Houston group is also planning the next meeting for the fall and celebrated the 4th of July with their annual BBQ. The Florida group had 52 patients, caregivers, doctors, and medical residents attend their April meeting. The Southern California/LA group recently planned a delicious lunch for almost 50 people and invited Dr. Woodley from USC and Dr. Fairley from the University of Iowa to speak about research and treatment options. Many members of the Boston group volunteered at Yankee Dental Congress, and the Tri-State/NY group staffed the Greater New York Dental Meeting in order to educate dentists. It’s been an amazing year, and I can’t wait to see what all of these groups will accomplish.

We’re always looking to expand our network, so please contact me at becky@pemphigus.org if you’re interested in starting a support group in your area.

Patient Education Calls
The IPPF offers frequent Patient Education Calls featuring leading P/P physicians and scientists. Calls last an hour and feature a presentation followed by a question and answer session. This year, more than 500 people have registered for these calls. After the call, a recording is made available via the IPPF website.

Peer Health Coaches (PHC)
The IPPF offers a service to our community where patients can speak directly with trained coaches. Our coaches are patients themselves and vividly remember what it was like to feel overwhelmed and under-informed. PHCs have the ability to relate, help reduce anxiety, and educate others from a patient’s perspective. Our trained coaches can provide information on the disease, treatments, and ongoing research.

PHCs are very active in our community and you might recognize their names: Mei Ling Moore, Janet Segall, Rudy Soto, Jack Sherman, Marc Yale, and Becky Strong. Each coach provides a comfortable and unbiased environment to share your questions or concerns. They all enjoy speaking and emailing with you to understand what’s going on and want to help make life better for everybody in our community. If you have a question and don’t have an answer yet, please submit your question to “Ask A Coach” on pemphigus.org and somebody will be in touch with you shortly!

Doctor Referral List
We know how hard it is to find a physician to diagnose and treat P/P. To help patients find physicians experienced with P/P, we offer a doctor referral list. These doctors are located in almost every state across the US. We have an international list of providers, as well.

We regularly update our referral list. If your physician isn’t on the list, or you know of one that should be, please let us know. To receive a copy of the doctor referral list, please email info@pemphigus.org

Website
The IPPF website is a wealth of information to help you understand your disease better, find prescription information, reach a peer health coach, and inform you of upcoming events. There’s also information about current research initiatives, publications, and clinical trial information. We encourage you to also visit the IPPF’s news site, PemPress (www.pempress.com), to read articles focused on advocacy, awareness, patient support, and the latest IPPF news.

RareConnect
While RareConnect isn’t a web group run by the IPPF, there’s a link on our website to easily access this site. It’s a safe, easy-to-use platform where rare disease patients, families, and patient organizations can develop online communities and conversations across continents and languages. RareConnect partners with the world’s leading rare disease patient groups to offer global online communities allowing people to connect around issues which affect them while living with a rare disease. It’s easy to read patient testimonials or share your story. The site translates stories or questions in the discussion groups into any language to help you learn from other patients. It’s a great resource.

Please consider making a donation to help the IPPF continue these services. We strive to improve the quality of life for all people affected by P/P through early diagnosis and support. The largest way we can make an impact is through these programs.
20th ANNUAL PATIENT CONFERENCE

• World-renowned speakers on plenary panels
• Local bullous disease experts
• Patient & caregiver workshops

HOTEL & VENUE

Hyatt Regency Newport Beach

• IPPF room rate starts at: $187/night
• Book online: www.pemphigus.org/newport2017
• Book by phone: (888) 421-1442
  (Reference "2017 IPPF Patient Meeting")

ENTERTAINMENT

Professional ELTON JOHN TRIBUTE ARTIST & PV Patient KENNY METCALF + more!

FRIDAY, SEPTEMBER 15
Pemphigus & Pemphigoid Intro Sessions Welcome Reception

SATURDAY, SEPTEMBER 16
Conference Sessions: 9:00am to 5:00pm Cocktail Hour Awards Dinner & Entertainment

SUNDAY, SEPTEMBER 17
Conference Sessions: 9:00am to 12:30pm
Print Name (as you want it to appear on your name badge) | Organization/Employer Name (Corporate Sponsors Only)
---|---

I am a □ Patient (PV, BP, etc) □ Caregiver □ Friend □ Other ________________________________

Mailing Address: Street □ Home □ Work

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### Patient Conference Registration Fees

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<td>Includes all sessions and workshops, as well as our Annual Awards Celebration and Dinner on Saturday night with a performance by professional Elton John tribute artist (and PV patient) Kenny Metcalf! Additional entertainment to be announced. Check pemphigus.org/newport2017 for details.</td>
<td></td>
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<tr>
<td>Conference Registration Only: $150.00 per person</td>
<td>□</td>
<td>x $150</td>
</tr>
<tr>
<td>You will be registered for all plenary sessions and workshops on Friday, Saturday, and Sunday at the Hyatt Regency, Newport Beach. Also includes light breakfast, breaks, Saturday lunch, and conference materials.</td>
<td></td>
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</tr>
<tr>
<td>Saturday Awards Dinner Only: $100.00 per person</td>
<td>□</td>
<td>x $100</td>
</tr>
<tr>
<td>Cocktails, Dinner, Awards, and Entertainment!!</td>
<td></td>
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</tbody>
</table>

**Scholarship Donation.** Please help someone else attend this year’s conference.

$ |

**Tax-Free Donation.** Help support current and future programs and research.

$ |

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**Total Enclosed** $ |

- □ Check/Money Order made payable in U.S. funds to IPPF
- □ VISA □ MasterCard
  - Card #: ________________________________
  - Exp. Date: __ / __
  - Security Code: __ __ __ __
- □ AMEX

Billing Address (if different from above): ___________________________________________________________

Signature: ________________________________________

Indicates you agree to have your card charged.

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**WAYS TO REGISTER**

- Online: [www.pemphigus.org/newport2017](http://www.pemphigus.org/newport2017)
- Phone: 855-4PEMPHIGUS (855-473-6744)
- Contact your Peer Health Coach
- Mail this completed form with payment to:
  - IPPF 2015 Patient Conference
  - 1331 Garden Highway #100
  - Sacramento CA 95833

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**OTHER ATTENDEES (as indicated above)**

Enter information as it should appear on badge:

<table>
<thead>
<tr>
<th>NAME</th>
<th>CITY &amp; STATE</th>
<th>DISEASE OR ROLE*</th>
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</tbody>
</table>

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

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**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 September 1, 2017, we will refund registration costs less $25 administrative fee. Due to the contractual agreements for food, beverage, and material costs, cancellations postmarked between September 1 and September 15, 2017 may be refunded up to 50% of the registration fees. We may be unable to make refunds after September 15, 2017. We will gladly transfer your registration to another person (scholarship) or credit it as a donation.
2017 IPPF Patient Conference
HOSTED BY DR. SERGEI GRANDO & DR. JOEL LAUDENBACH
September 15-17
Newport Beach, California
pemphigus.org/newport2017