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Welcome to the patient services edition of the Quarterly! We are certainly “All About Patient Services,” and this issue contains a lot of information about how those services impact patients and caregivers.

Thank you for your continued support of the IPPF. Your donations make our patient services possible, and we couldn’t do this without you. We all share the same vision of finding a cure for these diseases, so please consider becoming a Healing Hero today. Our Healing Heroes are beacons of hope: www.pemphigus.org/hero

If you’re a patient, you’ll find this issue filled with voices of other patients who understand what you are going through. Reading these messages, I hope you’ll be inspired to get involved like Awareness Ambassador Janice Rucinski; Peer Health Coach Rudy Soto; and clinical trial participant Odette Miller. They all have turned some of the hardest experiences of their lives into positive outcomes for others.

You are not alone on this journey—learning about your options can provide a sense of hope. Yes, “the ride may still be bumpy,” as Terry Wolinsky McDonald, PhD, acknowledges in her article, “Mental Health Options for P/P Patients.” But as Allison Aubuchon reminds us in her story, “the IPPF is a great community offering encouragement and advice.”

We are here to help you, so please take advantage of all the patient services we have to offer. Whether it’s finding a doctor or contacting a Peer Health Coach for advice, we want to help you manage your condition. We offer in-person disease education at the IPPF Annual Patient Education Conference and online education through Patient Education Series webinars. The IPPF also connects patients through local support groups, social media, and the online discussion forum on RareConnect. All this and more can be found on the IPPF’s website: www.pemphigus.org

The IPPF team is honored to support you, and we want you to know that you can count on us. We hope you enjoy this issue and reading about the wonderful patient services that the IPPF provides. Whether we are supporting disease awareness, advocacy, research, or educating the medical community, together we are improving the lives of all people affected by pemphigus and pemphigoid!
Cicatricial pemphigoid, or mucous membrane pemphigoid (MMP)—what’s that? My diagnosis was confirmed mid-2015, following a severe blister on my gum that popped, became ulcerated, and bled. It felt like razor blades carving through burnt gums when I attempted to brush my teeth, use mouthwash, eat, or drink through a straw. After a few visits to my dentist and no sign of improvement, I insisted on seeing a periodontist as I was concerned that it was potentially mouth cancer. After a biopsy, the results indicated that I had MMP. At that time the doctor prescribed me with betamethasone and told me to inform my family doctor, eye doctor, and gynecologist in case other breakouts occurred. However, he did not refer me to a dermatologist.

When I informed my family doctor, I was immediately connected with a dermatologist. While the dermatologist was informative and patient, that visit turned my world upside-down with overwhelming fear. I couldn’t grasp why my body was attacking itself, and no one could tell me why or what triggered this condition. Overall, I’m pretty healthy, aside from the fact I could lose a few pounds. But I hadn’t had any major health concerns before this bomb was dropped on me.
I had never felt so alone. I didn’t know anyone with this condition to reach out to for help. Many times, I wanted to scream at my family because, as much as I wanted them there, they didn’t understand. So, I became distant. I didn’t want them to look at me as sick and different because as a mother, I felt like the problem-solver and the one who cared for others. But this time I felt defeated.

A year later, my dermatologist introduced me to the IPPF. I reached out and connected with Becky Strong, and she was the ear that I had been looking for. I could talk and cry all at the same time and never felt like I was overreacting or being talked about after I left the room—she understood what I was going through.

In September of 2017, my husband and I attended the Annual IPPF Patient Conference in Newport Beach, CA. This conference was more than I expected. The tragic stories shared by folks struggling with pemphigus and pemphigoid were both heart-wrenching and uplifting. I met many individuals with these conditions and got to hear from various doctors who shared insights on the diseases and their available treatments.

The biggest takeaway was learning about how many cases start in the mouth and are misdiagnosed by dentists. By the time a diagnosis is confirmed, the condition may have spread to other areas of the body, making it even more life-threatening. During the conference, it hit home how rare this disease is. I felt like I needed to get involved by becoming an IPPF Awareness Ambassador.

Since then, I have participated in spreading the word to dental offices about the importance of early diagnosis. This past May, I was asked by Becky Strong to participate in the Annual Michigan Dental Association Conference in Lansing, MI, to help educate the dental community. This was one of the most eye-opening and rewarding awareness initiatives that I’ve participated in. Over two-and-a-half days, we connected with over 300 dental professionals and shared our stories of symptoms, the diagnostic challenges of pemphigus vulgaris (PV) and MMP, and why early detection is so important to the well-being of patients.

It was very rewarding to experience how many of those within the dental community were engaged and thankful for the information we shared, particularly those who then suspected they might have patients with early signs of these diseases.

I look forward to participating in future events and encourage all individuals with a form of P/P to get involved by spreading the word on the importance of early diagnosis. We are the best voice, and every little bit of help can go a long way.

Janice Rucinski has held positions in the advertising business for 20 years including, Vice President, Negotiations Manager, and Associate Digital Director of Media Strategy. She launched Janice Irene Photography, LLC in 2014. She loves spending time with her family—her husband of 41 years, three children, and five grandsons.

Find a Doctor: IPPF Physician Map

The IPPF is excited to announce the launch of its Find a Doctor online P/P physician map. The map provides patients with contact information for medical and dental professionals familiar with P/P.

Access the map at: www.pemphigus.org/find-a-doctor
Years ago, when pemphigus and pemphigoid patients (P/P) were first diagnosed, their journeys usually began with a head-first dive into unknown and confusing literature, research, and self-education. Today, the internet makes information and support much more accessible. All patients have to do is search for “pemphigus” or “pemphigoid” online, and they will find the IPPF.

It used to be that receiving a P/P diagnosis was like being thrown into some kind of parallel galaxy; it was a lonely and terrifying place. Now, because of IPPF outreach, online support, and Peer Health Coaches, there are real people to connect with who can answer a wide variety of questions and guide newly diagnosed patients to doctors, resources, and support groups.

These support systems are in place to work with and serve patients and their families. Still, even with access to support, the ride may still be bumpy. After all, even if disease symptoms are mild, life will never be exactly the same as it was. This means both "accommodation" and "adaptation" are necessary—for the disease process itself and for dealing with family, friends, coworkers, new medications, and limitations. And while Peer Health Coaches help guide patients along their individual journeys, they are not trained (or expected to) provide direct mental health care. Mental health care is best left to the expertise of those trained in the field.

While primary care physicians and dermatologists can prescribe psychotropic medications such as antidepressants or anxiolytics (anti-anxiety medications), this is not their specialty or area of expertise. Psychiatrists are the prescribing professionals with the most knowledge in this area. “A psychiatrist is a medical doctor (an MD or DO) who specializes in mental health, including substance abuse disorders. Psychiatrists are qualified to assess both the mental and physical aspects of psychological problems.” (American Psychiatric Association, www.psychiatry.org).

If symptoms and feelings are not too serious, a patient may not need the services offered by a psychiatrist. However, a primary care physician may refer patients to a psychiatrist for a consultation to make that decision. (A psychiatrist will not always prescribe medication or ask patients to return each week.) The right medication(s) can often take the edge off of feelings of sadness or high anxiety. Why feel worse than necessary? These feelings do not necessarily mean you are unable to complete school, work, or day-to-day tasks, but they can make them more difficult.

Sometimes small doses of medications are enough. Sometimes patients don’t need prescriptions at all. And, sometimes all that is needed is to talk to a trained, objective professional. Mental health professionals such as counselors, therapists, psychotherapists, and social workers are trained and licensed to listen objectively and to provide necessary feedback and appropriate interventions (e.g. psychodynamic, cognitive, behavioral, or mindfulness-based therapy). It’s important to research a mental health professional’s credentials prior to your visit to be sure they are qualified to provide such services.

Psychologists are another resource, and they usually have PhD or PsyD degrees. “Practicing psychologists have the professional training and clinical skills to help people learn to cope more effectively with life issues and mental health problems (American Psychological Association, www.apa.org).

When looking for a therapist, counselor, psychiatrist, or psychologist, it is important to make sure the professional is comfortable and has experience with chronic or serious illnesses. You may need to interview and research them to determine this. It’s likely that they
will be unfamiliar with P/P, but it’s important for them to be open and willing to become familiar with the disease. If they aren’t willing to do this, it may be a red flag.

Though the IPPF has done a spectacular job of raising awareness, pemphigus and pemphigoid are still not household words. Unless people have specific training or are family members, relatives, or close friends of a diagnosed patient, it is unlikely that they will ever have heard of P/P. However, the work and dynamics of the IPPF mean that no one with P/P has to be alone or isolated on their journey. It is important for those affected by these illnesses (patient or caregiver) to recognize the mental health aspects of dealing with this new reality. Finding the right kinds of support from people who are willing and able to address these issues is an important part of the treatment, making the ride less bumpy.

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.
Autoimmune bullous disorders (AIBD) involve a wide variety of diseases, mainly pemphigus and pemphigoid (P/P) groups. Pemphigus vulgaris (PV) and bullous pemphigoid (BP) are the most frequently reported AIBD in Turkey from these groups. Pemphigus is the most common, affecting adults between the ages of 40 and 60 years. The incidence of pemphigus in Turkey is like that of other countries in Southeast Europe. The mean incidence of pemphigus was 4.7 new cases per million people per year (95% confidence interval (CI) 4.1-5.4) in the latest prospective research. BP is thought to have a lower incidence in Turkey, but there is no epidemiologic data of its incidence in Turkey. BP is generally seen in those above 70 years of age.

All dermatologists are trained concerning the diagnosis and treatment of patients with AIBD during specialty training. However, the long-term treatment plan for patients with AIBD is the responsibility of an experienced dermatologist. In Turkey, this is often a hospital-based dermatologist in a tertiary referral center. University hospitals and Research Education hospitals are accepted as tertiary medical centers in Turkey. In these centers, patients can find adequate diagnostic tests, multidisciplinary approach for the disease, and current treatment options for AIBD. Figure 1 shows the certain centers for AIBD in Turkey.

The Turkish Dermatology Society has a group of experts (Bullous Diseases Task Force) who are dedicated to providing the most current information about AIBD and treatments, publishing informational brochures to patients and hospitals, running annual meetings for future goals of the Task Force, and conducting patient-oriented research. Experts belonging to the Task Force are usually involved in creating European and other international guidelines for AIBD, and they participate in trials that have important outcomes related to understanding the etiology of these diseases and searching for new therapeutic options.

Turkish bullous disease experts mainly follow European guidelines and recent recommendations from the International Panel of Experts for diagnosis, treatment, and management of these diseases. The first step for each patient is to confirm the diagnosis of bullous disease. Two skin biopsies are necessary for diagnosis: one for histologic examination from lesional skin and another for a direct immunofluorescence test (DIF) from perilesional skin. The third sample is serum for immune serologic examination using the commercially available anti-Dsg1 and anti-Dsg3 ELISA kit and/or indirect immunofluorescence test (IIF), and for BIOCHIP in some centers. These tests are usually available in tertiary referral hospitals such as the above-mentioned centers.

After definitive diagnosis, certain laboratory workup is done before corticosteroid and/or immunosuppressive therapy: complete blood count; creatinine; blood electrolytes; transaminases; alkaline phosphatase; total serum protein; albumin; fasting serum glucose; Hepatitis B, C, and HIV; chest X-ray; ß HCG to exclude pregnancy in females of childbearing age; and bone densitometry. The severity of disease is usually evaluated using the Pemphigus Disease Area Index (PDAI), Bullous Pemphigoid Disease Area Index (BPDAI), and/or Autoimmune Bullous Skin Disorder Intensity Score (ABSIS). End points and therapeutic response are evaluated as described in the consensus statement published by Murrell et al.

The combination of systemic corticosteroids and corticosteroid-sparing immunosuppressive drugs, mostly azathioprine, is regarded as standard first-line therapy by most Turkish experts. They are available under the Turkish Medicare system after a definitive AIBD diagnosis is made. In the last five years, rituximab has often been used as an adjuvant therapy because it is shown to be a safe treatment option with steroid sparing effects. Rituximab can be used in conventional treatment-resistant patients with a report of off-label
use approved by the Social Healthcare Institution in Turkey. Foreigners can also get rituximab therapy in Turkey after sending the necessary documents to the Turkish Ministry of Health. It costs approximately $2,000 (US) in a state hospital. University hospitals in Turkey treat patients from Eastern European countries where rituximab is not available, and they receive rituximab therapy in Turkey according to the procedures mentioned above.

Intralesional injections of corticosteroids (triamcinolone acetonide) are recommended for isolated lesions of the oral mucosa, lips, and skin, as well as topical treatment with potent corticosteroids (such as clobetasol propionate) applied directly to erosions for use in combination with systemic therapy. Furthermore, antiseptic containing baths, vitamin D, and calcium supplementation is recommended at the time of the initiation of glucocorticoid treatment. Vaccinations against seasonal influenza and pneumococci should be given. Patients are also encouraged to receive oral care and sun protection. During the disease course, follow-up visits are offered every two weeks until clinical disease control is achieved. After that, monthly clinical follow-ups are recommended for three months. When patients achieve remission on therapy, they can be seen on a bimonthly or trimonthly basis.

Patients and their families are always informed about the disease, particularly about the clinical course and prognosis; treatment; relapse signs; potential triggers such as certain foods, drugs, operations, and physical trauma; and possible adverse events associated with treatment.

The Turkish Dermatology Society offers a wealth of information concerning autoimmune bullous diseases. For more information, patients can visit: [http://www.turkdermatoloji.org.tr](http://www.turkdermatoloji.org.tr)

There are no specifically organized support groups for patients with AIBD in Turkey. The following list contains the names of some experts and centers of AIBD (Figure 1):

- **Adana**: Başkent Univ., Faculty of Medicine (Murat Durdu)
- **Ankara**: Ankara Univ., Faculty of Medicine (Hatice Şanlı)
- **Ankara**: Gazi Univ., Faculty of Medicine (Nilsel İlter)
- **Antalya**: Akdeniz Univ., Faculty of Medicine (Soner Uzun, Ayşe Akman Karakas)
- **Aydın**: Adnan Menderes Univ., Faculty of Medicine (Ekin Şavk)
- **Bursa**: Uludağ Univ., Faculty of Medicine (Emel Bulbul Başkan)
- **Diyarbakır**: Dicle Univ., Faculty of Medicine (Mehmet Harman)
- **İstanbul**: İstanbul Univ., (Cerrahpaşa) Faculty of Medicine (Yalçın Tüzün)
- **İstanbul**: İstanbul Univ., (Çapa) Faculty of Medicine (Rıfkıye Kıcık)
- **İstanbul**: Marmara Univ., Faculty of Medicine (Tülin Ergun)
- **İzmir**: Dokuz Eylül Univ., Faculty of Medicine (Şebnem Aktań)
- **İzmir**: Ege Univ., Faculty of Medicine (Bengü Gerçeker Türk)
- **Mersin**: Mersin Univ., Faculty of Medicine (Tamer İrfan Kaya)
- **Trabzon**: Karadeniz Teknik Univ., Faculty of Medicine (Savaş Yaylı)

**Figure 1: Treatment Centers for AIBD in Turkey**
Acknowledgments:
Ailsa Bilgic-Temel is working as a visiting fellow at St George Hospital and Sutherland Clinical School, UNSW, Australia. She is the 2018 recipient of the Turkish Dermatology Society – Prof. Dr. Hulusi Behcet (Long-term Research) Scholarship.

References

IPPF Research Symposium: Orlando, Florida

This past May, the IPPF hosted the research symposium Pemphigus and Pemphigoid: A New Era of Translational and Clinical Science in Orlando, Florida. The meeting brought together over 170 clinicians, researchers, industry partners, and patients from 13 different countries to discuss clinical trials and their underlying science. The symposium was held as a precursor to the International Investigative Dermatology meeting in the same location.

The IPPF recognizes the importance of facilitating discussion and collaboration among clinicians, researchers, and industry. Though pemphigus and pemphigoid are rare diseases, important advancements in research and treatments are being made around the world.

Meetings such as this symposium allow the best minds in the field to not only share the most up-to-date information, but also inspire each other to continue this important work.

Thank you to all who attended and participated!
The blistering diseases specialty clinic was first established in 1997 based within the Premier Specialists clinic and clinical trials center in the Sydney suburb of Kogarah, across from St. George Hospital. It is now one of Australia’s leading clinical trials centers and a center of excellence in dermatology providing clinical, research, and education services. It is affiliated with the Faculty of Medicine at the University of New South Wales (UNSW), where Dedee Murrell is a professor. Blistering disease clinics are held on Fridays and include dedicated fellows who are either dermatologists trained overseas who are learning more about blistering diseases for a year, or pre-dermatology fellows conducting clinical trials. The only other center specializing in autoimmune bullous diseases (AIBD) is at the Royal Melbourne Hospital in Melbourne, Victoria, with Professors George Varigos and Johannes Kern.

The center in Sydney has an excellent reputation for clinical trials, and we are currently conducting trials in several of these skin conditions, especially autoimmune bullous diseases. We established the Australasian Blistering Diseases Foundation in order to fund new research into the causes, diagnosis, and treatment of blistering diseases. We are involved in multi-center, prospective, randomized controlled trials, which are necessary when looking at rare diseases like pemphigus and pemphigoid. These studies often provide new therapies for these life changing diseases and show how effective working collaboratively can be. Moreover, we are sharing the results of the studies published in leading international journals to make sure they are taken up into clinical practice effectively and quickly so that patients can benefit. We aim to make trial visits as efficient as possible for patients and to provide better evidence for patient care.

Our center will undoubtedly continue to grow, instigating novel research concepts, expanding projects with collaborators, and continuing our dedication to training and mentoring medical students and fellows from across the globe and supporting them in establishing their careers.

The Australasian Blistering Diseases Foundation is a rich resource that offers a wealth of information concerning autoimmune bullous diseases. Visit http://www.blisters.org.au for more information.
What do we mean when we talk about patient services and patient support? For me, patient services include myriad features that define an organization like the IPPF: governmental advocacy, medical help and advocacy, program development, research, and awareness. Patient support also includes things that directly affect patients on an individual level, such as one-on-one peer support, annual and group support meetings, and discussion forums.

When the Foundation started in 1994, the first goal was to find people living with pemphigus vulgaris (PV). The internet was evolving slowly. We had an email address, but there was really no way to let people know who we were. So we relied on doctors to let patients know that they were not alone and there was a support system available. That was only moderately successful; however, I found a person doing research on autoimmune diseases, and they decided to do an interview with me to post online. We were found!
So many people felt alone and misunderstood. I got emails and calls every day from people looking for someone to talk to about this insidious illness, someone who would understand the physical and emotional rollercoaster that the disease and treatments were causing. Then people with pemphigus foliaceus started contacting the Foundation, wondering if we could put their illness under our umbrella. Sometime later, we were contacted by people with bullous pemphigoid (BP) and mucous membrane pemphigoid (MMP) looking for the same support. Since these were all similar autoimmune diseases affecting the skin and/or mucous membranes and the same treatments were used, the Foundation’s name changed. We went from the National PV Foundation, to the National Pemphigus Foundation, to the National Pemphigus Pemphigoid Foundation.

Then we started receiving emails from international patients, and I wanted everyone dealing with these conditions to receive the support they needed. So we brought people from other countries into our family and finally became the International Pemphigus & Pemphigoid Foundation. We contacted doctors worldwide and set up support group meetings in several different countries with the hope of reaching as many people as possible. Knowing how difficult it can be for people in developed countries to find good information on rare diseases like pemphigus and pemphigoid, imagine how difficult it is for people in countries where help is not as prevalent.

When I was diagnosed with PV in 1983 at 37 years old, it was devastating. I was sure that I was not going to live, and my daughter, whom I was raising alone, thought she was going to be an orphan because her father had died when she was just 14 months old. My family and friends got us both through this terrible time. I had a lot of physical support—but as much as I love my family, they didn’t understand what this felt like. No one in my immediate family had dealt with a chronic illness before, so they had no clue about the best way to deal with me. I felt very alone emotionally.

My first thoughts after being diagnosed were about how I was going to handle raising a child alone. At that time, I was only on prednisone because there was really nothing else that worked. Then I thought I could find a foundation and learn about the condition, or at least find out if there were others to connect with. But there was nothing. So, I went through the first 10 years on and off prednisone, hiding my feelings and my fears.

After achieving remission for the second time, I thought I wasn’t going to get this disease again. But it came back. I had had enough. I desperately needed to find others, so I started the Foundation. I knew in my heart that this was an important step toward connecting, not just for me, but for others as well. In a sense, I hated finding out there were others living with PV; on the other hand I had been looking for emotional support for so long. I also knew I could give emotional support to others, and it nurtured my soul. My life changed. The IPPF was my Chicken Soup for the Soul.

For a short while I wasn’t as connected to the IPPF. It was difficult not having that support system, but I understood PV very well and was in a good place with a no-drug remission. However, reconnecting with the Foundation showed me the importance of making and keeping these connections. Even in remission, those connections have been so important in my life. Knowing I could still help the P/P community gave me back that sense of family. I know that once remission is reached, stepping away can be the best way for some people to find a sense of peace. For me, keeping those connections is what helped me find peace. I was brought up to believe that we are all connected as human beings on this earth and that helping one another is a blessing.

I’ve learned a lot about P/P over the years. I’ve also learned about insurance issues; how the politics of healthcare can affect our recovery; the importance of fostering relationships with the medical and dental community; and how to deal with the mental health issues that can affect people with illness. For me, being able to impart any of this information is what gives meaning to my life. There are a lot of different ways to help others, and I encourage everyone to find what makes sense to them.

Janet Segall is the Founder of the IPPF and a PV patient since 1983. She is a Peer Health Coach and works in Sacramento, CA in the mental health field.
In February 2017, the day before my scheduled C-section for our second child, a small itchy spot appeared on my chest. I thought it was a bug bite, but it did not go away. A week or so later, similar, itchy bumps started appearing on my stomach.

Knowing I’d just had a baby, my local dermatologist considered pemphigoid gestationis (PG), “an allergy to the placenta.” This was good news to me, since it sounded temporary. I was given topical ointment, and I went home presuming it would all end soon.

A few weeks later, the spots were still spreading. I was placing ice packs all over my body, even the bottoms of my feet, to bear the itch. Warm water in the shower made it worse, as did every touch or hug. I was desperately Googling my condition, searching for anything that would give me hope or relief.

About a month into my worsening condition, despite being on 20 mg of prednisone per day and topical treatments, lesions were expanding all over my torso and legs. I was bumped up to 40 mg of prednisone per day. Doctors did a second, deeper biopsy and found that my condition was actually pemphigus foliaceus, a rare immune response resulting in autoantibodies attacking the “glue” that holds skin cells together.

This diagnosis came with waves of hard-to-swallow news. There is no cure. It’s unknown what causes it (like many autoimmune diseases). I immediately increased my dosage of prednisone to 60 mg per day and began taking a drug called CellCept®, which meant I couldn’t continue breastfeeding. I was already in pain holding my then three-month-old against my skin. Now, I could no longer give him the benefits of breastfeeding due to this new medication.

My local doctor also told me to prepare for a Rituxan® infusion as soon as possible. I regretfully did not heed this advice right away, as a specialist I was also seeing suggested to save this for later in my treatment.

Diagnosis in hand, I enlisted a naturopathic professional who suggested some herbal supplements. But I was on so many medications I don’t think the natural remedies had any chance. After some research, I started a Paleo Autoimmune Protocol diet, which—if anything—gave me something I could control during a time of uncertainty. It also helped me combat some of the negative side effects of the prednisone.

But I still wasn’t getting better. I spent months on 60 mg of prednisone and CellCept®, feeling terrible from the medications while swaths of my skin turned into open wounds. I wore gauze and Vaseline under my clothing every day to keep my skin from sticking. It was a nightmare, especially during the hottest Florida months. During a time when I was looking forward to

Comfortable in My Imperfect Skin

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recovering from pregnancy and being a good caretaker to my two sons, this seemed like a cruel joke. Getting ready to go anywhere included an entire operation, hiding as much skin as possible and dabbing makeup on the spots now showing on my neck and hairline. I was on a rollercoaster: a glimmer of hope, then the crushing realization of realizing the “rash” was slowly spreading.

By wearing scarves and high necklines, I could disguise my lesions fairly well, but the months of higher-dose prednisone started to change the shape of my face. I told people I was dealing with an autoimmune “skin thing,” and maybe showed them a few spots on my neck. But if I’d shared how bad it was, I would have burst into tears. During lab visits, I felt like I was in a fog, defeated and numb to the routine. I lost track of how many times I was on antibiotics, but looked forward to them because I felt safer from infection. They also made the wounds dry out and look better.

My lowest point was a trip to the ER, when an infection on my chest spread to my lymph nodes, bringing on a 104-degree fever. I felt hopeless, thinking that my children were destined to have a mother who would always be fighting never-ending itchy spots. Any feelings of invincibility I had were shattered. It was hard on my whole family.

That’s when my local dermatologist told me I needed to do the Rituxan infusion. He was a champion for me in pushing this, and I am so grateful. The Rituxan infusion was my miracle. I received two doses, two weeks apart. A few weeks after my second dose, the first signs of healing appeared. The lesions started to slowly recede, and my hope grew. We’re talking glacial progress, but it was the right direction. I was able to taper off prednisone and come out of the fog, a process that took months and felt like a special kind of full-body tired that no amount of coffee could help. I am also still returning to my “normal background color” as my local doctor calls it.

What I thought would be a few weeks of discomfort turned into a health journey. It is scary to think of my pemphigus foliaceus flaring up again, but I’ll know what to do (sooner) if there is a next time. It has been a life reset. A frequently cited pemphigus foliaceus trigger is stress, and looking back to when this began, I was a bundle of nerves worrying about C-section recovery, maternity leave while keeping my new business afloat, a list of highly unnecessary home projects before baby’s arrival, and how we’d manage it all during my husband’s busiest time of year. My heart raced daily for weeks during that time, and I remember having trouble sleeping. I feel strongly that while I was probably wired for pemphigus foliaceus, it was my body’s reaction to a prolonged state of stress.

My skin may never be the same, and I’m OK with that.

At 35, my priorities have never been clearer: I want to be healthy, happy, and here for my family. Taking care of myself is non-negotiable if I want to take care of others. I am learning to create more breathing room in my life, be mindful, and do more of what brings me joy. I’ve also reduced the amount of inflammatory foods in my diet. Whether it’s proven to improve pemphigus foliaceus or not, eating more real, healthy foods makes me feel good. My skin may never be the same, and I’m OK with that. I feel more comfortable in my skin—imperfect or not—than I have in a long time.

Today, I am counting my blessings. Our now one-year-old is happy, healthy, and plump, and I can cuddle him close. Our four-year-old prayed for my “spots” to get better, and I can see the joy on his face when I tell him how great I am doing. I am thankful for the patience of my husband, who never stopped telling me I looked beautiful, even on the worst days. And I am thankful for the doctors here in my hometown of Tallahassee who were able to diagnose me and provide the care I needed. Thank goodness for their awareness.

If you’re newly diagnosed, know you are not alone. The IPPF is a great community offering encouragement and advice. We are fortunate to live during a time when this organization exists to further treatment research and increase awareness and patient support.

This has been the hardest thing I’ve ever experienced. In remembering how bad it was, I appreciate healthy days like today even more. When I was at my worst, I needed someone to say these words, so I will gladly tell you: You will get through this. This is not your forever, and you will celebrate healthy days again.

Allison Aubuchon is a PF patient who was diagnosed in 2017 and is in remission. She is a public relations consultant living in Tallahassee, FL, with her husband, Josh, and their two young boys.
The IPPF’s most important objectives are to provide patients and doctors worldwide with information about pemphigus and pemphigoid (P/P) and to provide patients and their caregivers much needed comfort and support so they can continue to live active, productive lives. To accomplish these objectives, we offer a number of patient services to our community.

The IPPF’s Peer Health Coach Program

Peer Health Coaches (PHCs) are P/P patients who help more than 1,200 patients and caregivers each year. These specially trained PHCs reduce patient anxiety and uncertainty while providing unbiased disease and treatment knowledge. PHCs engage with the community through social media, emails, phone calls, and in-person support. The goal of our PHC program is to help every person who needs assistance in the shortest time possible. Currently there are six coaches, all of whom are happy to help. If you have a question or would like to connect with someone who understands what you are going through, connect with a PHC online: www.pemphigus.org/ask-a-coach

Patient Education Series

The Patient Education Series offers webinars that feature leading P/P physicians and scientists. These webinars can be accessed live online or via phone. All webinars are recorded and can be downloaded through the IPPF website. Webinars are structured to give the guest speaker time to present and then answer incoming questions from the community. This is a great time to listen, learn, and submit a question to one of our leading experts.
This year’s topics have included Mental Health, Advocacy and Research Updates, Awareness Program, and Rituxan® as a Treatment Option. To register for an upcoming webinar or to listen to a past recording, visit www.pemphigus.org.

Local Support Groups

We know that it’s important to connect with others who understand what you’re going through. Our local support groups provide an in-person setting to build friendships and share experiences. We currently 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 support groups are open to all people affected by P/P. Information about upcoming meetings or how to start a group in your area can be found at www.pemphigus.org/events

Physician Referrals: Find a Doctor

We know that it can be a challenge to find the right team of doctors to help treat P/P. The average patient sees 5 doctors over 10 months before they receive a correct diagnosis. The IPPF has a new Find a Doctor online map to help connect you with a physician who is knowledgeable about P/P. The map has been developed from contact with P/P treating physicians, recommendations from patients, and referrals from other physicians. It also includes international physicians. You can find doctors’ contact information, websites, and get directions to their offices. Access the Find a Doctor map at www.pemphigus.org/find-a-doctor

Annual Patient Conference

The IPPF is heading south to Durham, NC, for our 21st Annual Patient Conference. With world-renowned speakers and local bullous disease experts, the 2018 Patient Conference will be an exciting and educational event for any patient, caregiver, practitioner, researcher, or student in the bullous disease field.

The conference kicks off with “Dental Education Day” at UNC Dental School on Friday. We will cover the oral aspects of P/P and provide insight into disease management. Friday evening’s welcome reception will give all attendees an opportunity to meet others and share experiences.

Saturday and Sunday at the “Mansion on the Hill” DoubleTree at Research Triangle Park include specialized learning tracks on both pemphigus and pemphigoid, the Annual IPPF Awards Dinner with entertainment by world-renowned Elton John tribute artist (and PV patient) Kenny Metcalf, and personalized workshops designed to help patients thrive.

For more information, a full agenda, and registration visit: www.pemphigus.org/durham2018.

Natural History Study

Launched in March, 2017, the IPPF Natural History Study is a new patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US Food and Drug Administration (FDA). The study is designed to help the medical and research communities understand illness trends, treatment outcomes, disease burden, and some important demographic information. With this vital data from large numbers of participants, we can better advocate for resources to improve patient support, further doctor education, and accelerate research discovery. The more data we can collect, the better the information we can provide to researchers to find new treatments, keys to earlier diagnoses, and one day – a cure! Join the Natural History study at www.pemphigus.iamrare.org.

Other Resources

- IPPF website (www.pemphigus.org): Find disease-specific information about diagnosis, treatment options, physician referrals, research initiatives, and clinical trials; connect with a Peer Health Coach; listen to past Patient Education Series webinars; read past issues of the Quarterly; and catch up on the latest news on PemPress.
- RareConnect: This discussion forum is not run by the IPPF; however, RareConnect is a great place for rare disease patients, families, and patient organizations to develop online communities.
- Social media: Connect with the IPPF on Facebook (www.facebook.com/healourskin) and on Twitter and Instagram: @healourskin

Amethyst Yale is the IPPF Outreach Assistant. She currently lives in Colorado Springs and is pursuing her master’s degree in public administration at the University of Colorado. Her father was diagnosed with pemphigoid 10 years ago.
This story is all too familiar. My husband woke up with a severe sore throat one day that progressed to sores in his mouth, all over his body, and on his scalp. Eating was painful, and the area on his scalp grew larger every day. We began visiting doctors, which grew to five dermatologists, an internist, a dentist, a urologist, and a colon and rectal surgeon.

About a year later, he was diagnosed with pemphigus vulgaris (PV). Though the internet search that followed was revealing, it was not encouraging in terms of disease progression. We learned about the medications used to treat PV and the many relevant concerns while taking them.

Various medications were prescribed, but nothing worked. The daily reminder of pain and other physical symptoms was not improving our ability to cope. Depression was also something we faced now and then. Of course, our lives had changed in a way we had never experienced, and we didn’t know how to deal with it. As a caregiver I experienced anxiety, uncertainty, and feelings of complete helplessness.

We started looking at the IPPF and what it offered. We found people who had already been through this and were willing to share their knowledge. Through them, we finally found a dermatologist who knew how to treat the type of PV my husband has. This resulted in the...
in greatly diminished pain and control of the lesions on his body and scalp.

I started attending the monthly Patient Education webinars. Knowledgeable speakers with expertise in the disease were available to answer questions. The ability to ask specific questions relative to the monthly topic was invaluable. With a disease this rare, hearing from doctors and experts in the field helped to guide our next steps. We gained insight into what to expect with various treatments, and of course we were encouraged by success stories.

We learned about the Foundation’s awareness efforts of dentist and practitioner outreach to encourage early diagnoses and treatment. We were thrilled when we were told that our dentist was visited by an IPPF Awareness Ambassador. This made us feel that we were receiving the most up-to-date care. The IPPF Peer Health Coaches informed us about what to expect from treatment, which made us feel less anxious. They gave us the courage to go forward in a way that made us more relaxed and confident.

The IPPF coaches give selflessly of themselves and their time to help those who are new to the experience. Without them and the expertise of the doctors and specialists who host the Patient Education webinars, this journey would be more difficult to face. The lifeline that the IPPF staff, volunteers, patients, and caregivers have given to the community is a daily reminder that these are people who really care. We hope to meet these wonderful people someday because they have made us realize we are not alone.

A rare disease does not mean you cannot face each day with new hope. It has been a long journey, and we could not be where we are now without the IPPF. And for that, we are eternally grateful.

\*Pat Tapler’s husband is a PV patient. They live at the New Jersey shore with family and friends.*

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An Insider’s Perspective of the IPPF

**Amethyst Yale**

**It may sound cheesy**, but I find myself tearing up every time I think about all the ways the IPPF has touched my life, my family’s life, and all the patients who connect with the Foundation. My tears are from happiness, gratitude, and feeling welcomed into a community that understands. After many years of being connected to the community, I now have the privilege of working for the IPPF. I am delighted to be able to give back to the community who so graciously took me and my family in during our time of uncertainty.

Many of the IPPF staff members are either a pemphigus or pemphigoid (P/P) patient, a family member of a patient, or have a personal connection to the P/P community. It is incredible to work with a team that is passionate about the community we serve. We work as a team to spread awareness, connect with patients, provide peer support, advocate for the P/P community, build relationships with researchers and pharmaceutical companies, maintain relationships with congressional representatives, and offer educational support. I have only been the IPPF Outreach Assistant since January of this year, and I am amazed at how much the IPPF has already accomplished in the last few months!

When I think of the IPPF, I think of family. It is not just the people that I work with who are like family, it is everyone connected to the P/P community. To all the patients and family members, it is important to remember that you are not alone. You belong to our family, the IPPF family. We are always here to support you.

I encourage anyone who is interested to become more involved with the IPPF. I volunteered for several years before I became a staff member. It is a great way to connect with the community, build lasting relationships, and give back to other P/P patients. Together, we can look forward to a bright future for the IPPF family. If you are interested in getting involved, visit: [www.pemphigus.org/get-involved/volunteer](http://www.pemphigus.org/get-involved/volunteer)
The Good, the Bad, and the Ugly
PATIENT Q&A: ODETTE MILLER

Odette Miller, a Financial Coach with Financial Remedy & Associates, LLC, shares her story of living with pemphigus vulgaris (PV) for over two decades. In this question and answer session, Ms. Miller gives an account of her journey as a PV patient.

What is Good about PV?

For me, the good is the end result of being diagnosed. Once I was given my diagnosis and the medications that would put me on the road to recovery, gratitude became my new attitude. My thoughts were about getting back to a normal lifestyle, being able to watch my son (three years old at the time) growing up, pursuing my goals, and looking to the future.

I encourage patients to be more active in educating themselves about the clinical trial process to help find new drugs that will decrease the use of prednisone and/or put PV patients into remission. Getting patients more involved with innovation is important!

Have you ever participated in clinical trials?

Yes, in 2010 I participated in a Rituxan® trial where I received the drug. After learning all that I could about the trial’s process, I was very hopeful that I would be one of the ones in the remission percentage. During the trial, the drug cleared up my skin, however I did not go into remission.

A decision made with my physician care team was to try another round of Rituxan®. The trial had to be approved through my insurance company. Due to other life circumstances, the second round of Rituxan® never happened. But, at least my skin was clear!
In 2018 I participated in another clinical trial with the drug SYNT001 by Syntimmune. The drug is in the early approval stages to treat PV patients. I educated myself with the information associated with the trial and decided to participate. Again, I was hopeful that I would go into remission.

Although I was not a part of the remission percentage in the first round, the drug decreased my overall symptoms in active areas (mouth and scalp). Should I be presented with an opportunity to participate in a second trial, I would.

How did you first notice your symptoms?

At 18 years old, I had severe tooth pain. So, off to the dentist I went. The tooth was extracted, and I was sent home. Two weeks later I developed these small blood clots on the hard palate of my mouth. Eating and drinking became irritating, so I went back to the dentist to find out what was going on. I was told that they would go away within a couple of days.

They went away, but then I started to develop blisters all over my upper body. During the more than 12 months it took to be diagnosed, not only was my upper body covered with blisters, but I lost my hair, fingernail- and toenails, and my ability to speak (my tongue felt like it had been severed). These conditions made it impossible for me to perform my job, so I eventually lost it. Without an income and unable to pay my expenses, I had to move back home.

How did this affect your life and your relationships?

At 18 years old, this was a very scary time. One day I was thriving, and then within months I was rapidly losing weight and became malnourished because I was unable to eat. I was fighting for my life! Besides the blisters that covered my body—those in my mouth were the most ruthless of all.

At the same time, I was raising a very active toddler. The more than 12 months of going from doctor to doctor with no insight on my condition was very stressful and dismal. My overall state of life felt like a downward spiral.

What were your feelings throughout the process?

When I didn’t know what was wrong with me, my state was gloomy. The only things at this point that kept me going were prayer and my son.

For a little over a year, I must have visited over 15 different physicians. Throughout all the visits, I didn’t visit a dermatologist. It was not even suggested by other medical professionals, even though my skin was visibility affected.

Looking back over the past two decades, of course I think about how to help others like me gain an earlier diagnosis and not have to endure prolonged lack of treatment for PV. I don’t fault or blame others, but I do wonder how the process can be improved.

What were some of your cheerless moments?

Just not knowing what was wrong with me. Thinking that I probably wouldn’t be here to see my son grow up. Not achieving goals I had set for my life, these were some of my cheerless moments. Once I was diagnosed, my cheerlessness changed to a different feeling.

I was given prednisone to decrease/control the PV symptoms. Then I experienced unexplained weight gain with no direction on how to combat it. Then there were other side effects, such as bone loss. Due to an extended use of prednisone, I developed avascular necrosis (AVN), also called osteonecrosis or bone infarction, which is death of bone tissue due to interruption of the blood supply.

Now, I’ve been crying days on end thinking about the possibility of needing a hip replacement. Yikes! There’s a possibility I may need to have a hip replacement every 10 years or so. I also learned that my gums are receding more progressively than they should be, and I wonder if I’ll be able to wear partial or even full mouth dentures.

In closing, I am so grateful that living with PV has taken me full circle through all the phases of the good, bad, and the ugly. I am happy to be alive. I am forever grateful for my family, friends, and immediate team of physicians: Dr. Dolores Peterson, PCP, Moorestown, NJ; Dr. Germaine M. Camishion, Dermatologist, Moorestown, NJ; Dr. Kimberly Friedman, Optician, Moorestown NJ; Dr. Aimee Payne & Dr. VictoriaWerth, Dermatologists, University of Pennsylvania, Philadelphia, PA; the Pharmaceutical R & D Departments; and the connection with the IPPF. And, last but not least, I am eternally grateful for my relationship with my creator.
IPPF Peer Health Coaches were honored at the 2017 Patient Conference with Star Awards for their service to P/P patients.

IPPF Peer Health Coaches

Mei Ling Moore

Since pemphigus and pemphigoid (P/P) patients see an average of five doctors over ten months before receiving a correct diagnosis, they are likely fraught with a lot of stress—and blistering. The inability to know what to expect can bring fear and bouts of anxiety. Using the internet as a source of information can be scary, too.

IPPF Peer Health Coaches (PHCs) are pemphigus and pemphigoid patients who help more than 1,200 patients and caregivers each year. These specially trained PHCs reduce patient anxiety and uncertainty while providing unbiased disease and treatment knowledge. They provide patients and their caregivers much needed comfort and support so they can continue to live active, productive lives. PHCs have gone through similar difficulties and have also achieved remission, so there is a ray of hope to share with patients.

PHCs can provide a doctor referral list, helpful suggestions on dealing with painful blistering, foods that may be helpful to avoid, and possible side effects of medications. PHCs also consult with the IPPF Medical Advisory Board when necessary.

PHCs are available to patients and caregivers through both phone and email. Because they have also experienced misdiagnoses, horrible blistering, stressful times, treatment side effects, and the inability to focus on work, they can empathize with other patients.
Meet the Peer Health Coaches

**Mei Ling Moore** was diagnosed with 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 asked her if she would consider becoming a PHC. Mei Ling 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 organizes the Southern California support group. Mei Ling lives in West Los Angeles.

**Rudy Soto** 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 25 years and four children, ranging in age from 6 to 25.

**Janet Segall** is the founder of the IPPF. She was diagnosed with PV in 1983 and started the Foundation in 1994 with the purpose of giving people living with this very rare disease a place to find information and connect with others. Janet graduated with a Bachelor of Science degree in psychology. After college, she worked at several jobs in the mental health field. She was also the executive director of the IPPF until 2008. In 2009, Janet received her certification as a hypnotherapist. She began working with the IPPF again as a PHC in 2015. Janet resides in Sacramento and works part-time as an administrative assistant at a wellness and recovery center.

**Jack Sherman** 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 music education and is now an IT professional. He’s not very good at golf but loves flying drones. In his past life, Jack had a successful portrait photography studio and was a professional bass player. Jack lives in Seattle.

**Becky Strong** 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 has 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 also likes to swim, play the piano, and go for walks with the dog.

**Marc Yale** was diagnosed with mucous membrane pemphigoid in 2007. He 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 PHC for the IPPF. Marc is now the IPPF Executive Director and lives in Southern California with his wife and family.
The National Organization for Rare Disorder's (NORD) 35th Anniversary Celebration was held May 17, 2018, at the Andrew A. Mellon Auditorium in Washington, DC. It was an incredible night, not only to share in NORD's anniversary, but also to recognize those who have made contributions in the areas of innovation, advocacy, legislation, caregiving, and leadership with the Rare Impact awards.

The black-tie event was nothing short of a red carpet, Hollywood movie premiere. Attendees were greeted with champagne, professional photography, a gourmet meal, and entertainment. The emcee was Patricia Richardson, who is best known for her work on ABCs hit TV comedy “Home Improvement” as Jill Taylor. Patricia is a spokesperson for CurePSP, an organization that provides information and support for those with a rare brain disease called progressive supranuclear palsy (PSP). Patricia is well-versed in the pain and loss that a rare disease can cause, as PSP claimed the life of her father.

History

In the late 1970s and early ’80s, patients and families living with rare diseases were isolated and left with very little support in terms of treatment. A small organization called NORD was formed that would later be key in the Orphan Drug Act of 1983, which created financial incentives for the development of treatments for rare diseases. Since then, NORD has continuously represented the rare disease community.

Awardees

It was inspiring to listen to stories of the awardees that have made a difference within the rare disease community. One of those individuals is Dr. Robert M. Campbell, Jr, MD. He is the inventor of the Vertical Expandable Prosthetic Titanium Rib (VEPTR) device developed for the treatment of rare syndromes and disorders involving the malformation of the rib cage. This device has saved the lives of many children since 1989. Dr. Campbell was awarded the 2018 Lifetime Achievement Award.

Paradigm Shift

A paradigm shift is occurring in the rare disease community. Researchers, the government, healthcare facilities, the pharmaceutical industry, patients, and rare disease organizations are collaborating to address access to care, research funding, and policy. When doctors, researchers, and patients hug as they celebrate advances, I think we are truly entering into an age of amazing research, discovery, and hope.

My husband, Frank, and I were humbled to represent the International Pemphigus & Pemphigoid Foundation at the event and share the IPPF’s story with other rare disease organizations. I began to see how the IPPF serves patients affected by pemphigus and pemphigoid through its membership and collaboration with NORD, the Coalition of Skin Diseases, Derma Care Access Network, the International Alliance of Patient Organizations, the National Institutes of Arthritis, Musculoskeletal and Skin Diseases, part of the National Institutes of Health, and the American Academy of Dermatology so that P/P patients receive the best care possible.

Carolyn Fota lives in Stafford, VA, with her husband, Frank, and their three crazy cats. Carolyn enjoys walking, yoga, church, and writing.
Why I Became a Support Group Leader

Rudy Soto

I was diagnosed with pemphigus foliaceus over 10 years ago, and I have been in remission since November of 2016. Like many patients, when I was first diagnosed, I felt alone and didn’t know who to turn to for guidance, information, and support.

When I finally found the IPPF and reached out to them, I was put in contact with a great Peer Health Coach who understood what I was going through and made me feel less alone. We communicated over email several times, and I decided to attend an Annual Patient Conference. After meeting additional IPPF staff members, I knew that I wanted to help others like they had helped me, and I began my support group about three years ago.

With the help of the IPPF, we saw that there were P/P patients in my area and thought it would be beneficial, for other patients as well as myself, to start a support group in the Austin, Texas area. Being able to communicate with someone who knows and understands what you’re going through is very helpful and stress-relieving.

During support group meetings, we discuss different topics, such as diet, treatment options, and medications and their side effects. One of the most important aspects is that we support each other and keep in touch throughout the year. (Our families have grown very close.) The support group is small, but it is effective in the sense that we have all experienced similarities in our own journeys with this disease. Even though we may not have the same exact disease, the activity is similar, and we can all relate to each other.

Starting a support group in your area is not difficult. Notify the IPPF that you’re interested, and they will provide the materials and support needed. Email Becky Strong at becky@pemphigus.org to start a group today.

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.

Whether they are patients, family, friends, caretakers, medical professionals, or rare disease advocates, our Healing Heroes share the same vision:

No disease is too rare for a cure.

Become a Healing Hero today and receive a 50% discount to the 2018 IPPF Patient Conference

Learn more at pemphigus.org/hero
21st ANNUAL PATIENT CONFERENCE

- World-renowned speakers
- Local bullous disease experts
- Patient & caregiver workshops

HOTEL & VENUE
"Mansion on the Hill"
DoubleTree Raleigh-Durham at Research Triangle Park
- IPPF room rate starts at: $119/night
- Book by phone: (919) 941-6000
  (Reference "2018 IPPF Patient Conference")

ENTERTAINMENT
ELTON JOHN TRIBUTE ARTIST & PV Patient KENNY METCALF

FRIDAY, OCTOBER 12
Dental Education Day at UNC Dental School
Welcome Reception

SATURDAY, OCTOBER 13
Conference Sessions:
Specialized Learning Tracks for both Pemphigus and Pemphigoid
Awards Dinner & Entertainment

SUNDAY, OCTOBER 14
Conference Sessions:
Patient Focused Themes and Personal Disease Management
Print Name (as you want it to appear on your name badge)

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

Mailing Address: Street □ Home □ Work

City | State/Province | Zip/Postal Code | Country (other than US)

Daytime Phone: □ Home □ Work □ Cell ( )

Email: □ Home □ Work

### Patient Conference Registration Fees

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<td><strong>Complete Conference Package: $250.00 per person</strong></td>
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<td>Includes all conference presentations, workshops, events, awards dinner, and entertainment by Elton John tribute artist (and PV patient) Kenny Metcalf! Also includes “UNC Dental Day” on October 12.</td>
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<td><strong>Saturday Awards Dinner Only: $100.00 per person</strong></td>
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<td>Includes Awards Dinner and Entertainment. DOES NOT INCLUDE ANY CONFERENCE PRESENTATIONS OR WORKSHOPS.</td>
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**Scholarship Donation.** Please help someone else attend this year's conference. $

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

Total Enclosed $

□ Check/Money Order made payable in U.S. funds to IPPF

□ VISA □ MasterCard | Card # ____________________________

□ AMEX | Exp. Date: __ / __ | Security Code: ______________

Billing Address (if different from above): ___________________________________________________________

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

### Ways to Register

- **Online:** [www.pemphigus.org/durham2018](http://www.pemphigus.org/durham2018)
- **Phone:** 855-4PEMPHIGUS (855-473-6744)
- Contact your Peer Health Coach
- Mail this form with payment to the IPPF:
  
  1331 Garden Highway #100
  
  Sacramento CA 95833

### Other Attendees (as indicated above)

Enter information as it should appear on badge:

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

**Registration cannot be processed without payment.** Payment must be in US funds. All cancellations must be received in writing or by email to info@pemphigus.org. For cancellations postmarked on or prior to **October 1, 2018**, we will refund registration costs less $25 administrative fee. Due to the contractual agreements for food, beverage, and material costs, cancellations postmarked between October 1 and October 12, 2018 may be refunded up to 50% of the registration fees. We **may be unable to make refunds after October 12, 2018.** We will gladly transfer your registration to another person or credit it as a donation.
International Pemphigus & Pemphigoid Foundation
1331 Garden Highway #100 • Sacramento, CA 95833
855-4PEMPHIGUS • 916-922-1298
info@pemphigus.org | pemphigus.org

Patient Conference
Hosted by Donna Culton, MD & Ricardo Padilla, DDS

October 12-14 • Durham, NC
At Research Triangle Park
pemphigus.org/durham2018