We're Here to Support You
THE PATIENT SERVICES ISSUE
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Message from the Executive Director

Twenty-five years ago, a brave woman named Janet Segall stepped out from behind the shadows of her PV diagnosis and formed what is now the IPPF. In the early years, Janet knew she couldn’t be the only person with P/P and wanted to help others manage the myriad issues we all face after being diagnosed. Today, her courage continues to inspire people around the world and exemplifies the IPPF’s mission. Janet created the framework for the IPPF’s focus on advocacy, awareness, patient services, and research.

It’s hard to believe that half of 2019 has passed and the IPPF is celebrating its 25th Anniversary! The foundation has come a long way and we could not have done it without you. The number of people who have been helped and influenced by the IPPF is amazing. Peer Health Coaches have assisted over 425 individuals so far this year; support group leaders continue to connect local communities with personal help; fellow pemphigus and pemphigoid warriors continue to advocate and raise awareness about accelerating diagnosis times and improving treatments; and disease specialists are joining the IPPF Find a Doctor Map at a record pace.

In this edition of the Quarterly, you will read about many of our successes and efforts to carry on the vision that Janet Segall started 25 years ago. You will also learn about shaping the future by reaching out to state and federal officials; a PV patient’s commitment to advocacy in Washington DC; how the IPPF’s “Biopsies Save Lives” campaign is raising awareness for hundreds of medical professionals across the country; the variety of free patient services the IPPF offers to our community; and how one of our partners is developing a therapy that may improve the quality of life for patients with BP.

To celebrate the milestone of the IPPF’s 25th Anniversary, I hope you will join us in Philadelphia, PA, from October 11-13 at our annual Patient Education Conference. We’ve invited many leading disease experts to present on research and trends, educate about disease management, and answer your tough questions. Registration includes a 25th Anniversary Dinner to celebrate the impact we’ve made over the last quarter century. It’s a great opportunity for all those affected by P/P to celebrate each other and how far we’ve come.

Thank you for improving the lives of all people affected by P/P!

Marc Yale
IPPF Executive Director and MMP Patient
marc@pemphigus.org
I know many of you can relate to how it first felt being diagnosed with pemphigus or pemphigoid. After about a year of symptoms, I was diagnosed in 1983 and in a daze. I was in my mid-thirties and raising a child by myself. She was six years old.

Prior to receiving a diagnosis, I went to the dentist to get my teeth cleaned and mentioned to him that I had these body and mouth sores. He got a book from his shelf (no internet yet), opened the page to pemphigus vulgaris (PV), and read, “sores on the body, sores in the mouth—this could be pemphigus vulgaris.” As he read the description of the disease, I knew that was what I had. The last words he read were, “This is a fatal disease.”

I walked out of his office with my head down, feeling numb; his staff looked at me like I was a corpse. My first thought was about who would take care of my daughter since she had lost her dad when she was a baby. And I had plans—I was so looking forward to my plans! But the universe stepped in and said, “Oh, no—no plans for you!”

I wanted to find other patients. First, I called my doctor and asked if she had heard of a support group or foundation, and she told me there were none. I thought a lot about starting my own back then, but I hadn’t reconciled the fact that I had this disease. It took me 10 years before I decided to start a foundation.

I’d like people to understand that I never thought of myself as a person who would start a foundation. It just wasn’t me. I don’t know if it was the prednisone that changed my brain chemistry or just something genetic that had awakened in me. I remember the moment I decided, and I just knew I had to do it.

I had previously managed offices and knew how to put one together, but I didn’t know anything about starting a business. I found a book about starting a non-profit. I turned to page one and followed the directions. This was 1994. It took about three months to finish all the paperwork (I wasn’t sure what I was doing) and another three months and a few dollars to receive my nonprofit status. Getting nonprofit status was pretty easy back then.

I wrote letters to some of the prominent physicians I found on research papers and asked them to help me. I finally got a response from Dr. John Stanley at the University of Pennsylvania. He recommended that I
contact Dr. Grant Anhalt at Johns Hopkins University, who was looking for someone to start a nonprofit related to these diseases. So, I contacted Dr. Anhalt. By chance, the American Academy of Dermatology (AAD) was meeting in San Francisco, and I met with Dr. Anhalt there. He agreed to support my efforts.

The Foundation started at home. I was obsessed with it, and I needed to find others. Dr. Anhalt sent me the catalog of all of the dermatologists in the country from the AAD reference book. It took me three months to copy about 1,000 names and addresses of doctors into a database. I thought it would be a good idea to send a letter with my signature and Dr. Anhalt’s signature notifying people about the Foundation. It also included survey questions. I sent out several hundred letters specifically to doctors in large cities, and I received 75 responses.

I received one call from someone local, but I wasn’t able to find others. As luck would have it, my mother heard of a man in Berkeley, where I lived at the time, who was doing research on autoimmune diseases and HIV. I wrote him a letter. Three months later, he called me and said he would like to meet. His research was mostly on HIV, but he was willing to help. He had connections to an online reporter, and she interviewed me. After that, the Foundation really started to take off.

I started hearing from people across the country, so I created a newsletter. It provided information, but it didn’t look very nice. Luckily, a local patient offered his graphic design skills and a more professional newsletter was developed. Dr. Anhalt also put together the best professional bullous disease doctors for our Medical Advisory Board.

As more people joined the team, we moved into an office building. It was one room, but I was excited to be out of my house. As we grew and added more people, we eventually moved to a two-room office. We always struggled financially, and I was afraid we weren’t going to be able to sustain the Foundation. But we found great people who helped raise money, and we moved forward.

The Foundation started as a support network for PV patients, but we later added pemphigus foliaceus and pemphigoid. When the Foundation became the International Pemphigus and Pemphigoid Foundation (IPPF), it was exciting. Traveling overseas to Israel, Italy, and London to start support groups was thrilling. Uniting people from across the globe in their quest for answers made me feel that I had done something good.

For several years, the Foundation and I parted ways, but it moved forward. Will Zrnchik took the reins as Executive Director, and we grew. It was exciting. Then Marc Yale took over in 2016. In the meantime, social media became more popular and has helped people connect and learn about these illnesses.

I am in awe of all the wonderful doctors. I’m grateful to them for seeing that we are important even though our illnesses are rare.

Now I’m back with the IPPF as a Peer Health Coach because helping others learn to deal with their illnesses and giving them someone to relate to were always my main goals. There have been so many wonderful advancements in science over the past 25 years. When I was diagnosed, there was really only prednisone. When immunosuppressives came along, they helped patients get off of prednisone and its side effects. Then the more targeted Rituxan® came along, and now there are more advances in finding ways to stop signaling our antibodies to attack us.

I am in awe of all the wonderful doctors. I’m grateful to them for seeing that we are important even though our illnesses are rare. The people involved with the Foundation—the wonderful and kindhearted staff and volunteers—keep us knowledgeable and help us find support. With the Foundation’s trouble staying solvent in the past, I wouldn’t have imagined that we would last 25 years. I hope there will always be a place for us to work together (even when a cure is found) because there are always new people being diagnosed, and they will need direction.

I am so grateful for experiencing the growth and success of the first 25 years of the IPPF. For the next 25 years I hope for a cure for P/P and that more people will continue to care and help each other.

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.
The IPPF Awareness Program recently launched a strategic media and marketing campaign that stresses the importance of a biopsy when diagnosing pemphigus and pemphigoid (P/P). The Biopsies Save Lives campaign hit the road this past quarter, traveling to Texas, California, and Florida. We reached thousands of dental professionals through ads in state dental association journals and conference programs, outreach to local dental societies, social media, emails, and mobile alerts.

We kicked off the month of May by exhibiting at the Texas Dental Association Annual Meeting in San Antonio. We were excited to show off our updated booth with new pop-up signs and images to catch dentists’ attention. We even had a presentation on the exhibit floor, where Outreach Manager Becky Strong shared her diagnosis story as a part of an Educational Theater presentation. We went big to make sure that dental professionals in Texas know about P/P!

Next, we put on our IPPF sunglasses and visited sunny California to exhibit at the California Dental Association meeting in Anaheim. Dental professionals who stopped by our exhibit booth were handed our new educational material. This handout centers on a single take-away for dental professionals: “Biopsies Save Lives: 4 questions to ask your patient to determine if a pemphigus/pemphigoid biopsy should be considered.” This information not only helps dental professionals recognize the symptoms of P/P, but also goes a step further to emphasize the importance of a biopsy. We made a big splash and tried to make sure every dentist in California heard about us.

Most recently, we exhibited at the Florida Dental Convention in Orlando. Patient volunteers shared their diagnosis stories with dental professionals who stopped by our booth. As most patients can attest, the pathway to a correct P/P diagnosis is often long and winding with multiple referrals, misdiagnoses, and ineffective treatments. We spoke to hundreds of dental professionals about the Biopsies Save Lives campaign and reinforced the dental professional’s unique opportunity to accelerate P/P diagnosis times.

It was a busy few months, but our work isn’t finished. New York and the New England Region are up next!

Kate Frantz, MPH, is the IPPF Awareness Program Director. She lives in Michigan with her husband and daughter.
Sy Syms Foundation Continues to Support P/P Patients

Anna Lane

The Sy Syms Foundation has awarded a $100,000 grant to the International Pemphigus & Pemphigoid Foundation (IPPF) in support of the IPPF’s Biopsies Save Lives Campaign. This will be the seventh consecutive year the Sy Syms Foundation has supported the Awareness Program.

Since developing the Awareness Campaign in 2013, the IPPF has reached thousands of dental professionals and students. Due to its continued growth and impact, the Awareness Campaign transitioned into a permanent Awareness Program in 2017. This year the IPPF Awareness Program launched a media and marketing campaign that stresses the importance of a biopsy when diagnosing pemphigus and pemphigoid (P/P).

The new campaign centers on a single take-away for dental professionals: “Biopsies Save Lives—4 questions to ask your patient to determine if a P/P biopsy should be considered.” A new information card was created to help dental professionals both recognize the symptoms of P/P and emphasize the importance of a biopsy. The campaign’s focus includes spreading awareness by exhibiting at dental conferences, emailing dentists throughout the country, reaching out to local dental societies, presenting at dental schools, increasing visitors to the website, and training Awareness Ambassadors to reach local dentists.

“We are incredibly grateful for the continued support of the Sy Syms Foundation,” said Kate Frantz, IPPF Awareness Program Director. “This is a pivotal year for the Awareness Program. We’ve launched our Biopsies Save Lives campaign, which includes new resources for dentists, an increased focus on marketing and communications, and enhanced methods for getting our messages out faster to even more dentists. We cannot thank the Sy Syms Foundation enough for their support in our efforts to accelerate pemphigus and pemphigoid diagnosis times.”

About the Sy Syms Foundation

The Sy Syms Foundation was established in 1985 by retail entrepreneur and humanitarian, Sy Syms. His mission was to support education, and through his generosity the non-profit Foundation has affected the continued growth of many institutions of higher learning, medical research, and civic and cultural bodies. For more information on the Sy Syms Foundation, visit sysymsfoundation.org.

Anna Lane is the IPPF Communications Assistant. She lives in Denver, Colorado, with her family.

Thank you to the SY SYMS FOUNDATION and the UNGER FAMILY For their continued support of the IPPF Awareness Program
In my experience it seems like historically set cultural and gender roles have finally started to change in recent years. For example, divorce is more common. Women have become more financially independent, often in careers traditionally considered less female. More men take on increased responsibilities at home. The decision whether or not to get married or have children has evolved. As times change, many older traditions have been reevaluated. Responsibilities like cooking, cleaning, laundry, and grocery shopping may no longer have a direct correlation to a specific gender. From a psychological point of view this is encouraging and positive.

This kind of responsibility sharing can also help when a family member has a devastating illness and may be unable to do what they did prior to being diagnosed. However, it’s important for those supporting patients to remember that help doesn’t always need to be big or perfect. After all, one person cannot do everything, but everyone can do something. This can include picking up prescriptions, doing household chores, grocery shopping, or managing finances. There can be strength in simply being there for someone and trying to understand what they’re going through.

In my opinion, there will always be something that can be done to help and doing something always counts. Don’t ever discount what you get done, even if you think you came up short. Every single accomplishment counts, and when we come together, our important work and successes increase exponentially. After all, the IPPF started with just one person at a kitchen table. Now look at its legacy!

The IPPF website helps people find information about the history, symptoms, and diagnosis of pemphigus and pemphigoid (P/P). It includes information about the newest treatments available, experts in the...
field, doctor contact information, how to connect with a local support group or Peer Health Coach (PHC), and where to refer doctors or dentists that may not be familiar with P/P. Where else would you send people to learn about pemphigus and pemphigoid, from symptoms and diagnosis to the newest treatments and experts? Where else could you send newly diagnosed patients to get names of local doctors, local support groups, and one-on-one coaching? Where do you send your medical and dental professionals who are less knowledgeable about P/P to look up the most current information?

These resources are clearly not a one-person job. People with different skills and expertise must work together. There is a division of labor. Not everyone can lead or go to Capitol Hill, raise or contribute large sums of money, edit a journal, provide emotional support, or explain research in understandable ways. The division of labor keeps the organization together to allow the IPPF’s mission to move forward.

What started as one person’s idea and determination has evolved into an amazing foundation that uses the motivation and special talents of so many to achieve its goals. Nineteen years into my own pemphigus journey, I am so proud of all the different people and personalities who have made this possible. I encourage you to ask yourself what special talents or gifts you may have to contribute. Everyone can do something. No contribution is too small. Everything we do collectively can make a difference. And from a purely psychological point of view, it will make you feel better. Try it.

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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.

Ellen Levine Receives Harvard Med School Dean’s Community Service Award

Anna Lane

The IPPF is excited to announce that Ellen Levine, IPPF Patient Educator and pemphigus vulgaris (PV) patient, received the Harvard Medical School Dean’s Community Service Award for her work with the IPPF. The award identifies individuals whose dedication and commitment to community service have made an outstanding positive impact on the local and/or global community. The award includes a $1,000 donation to the IPPF.

Ellen lives in Boston and works for the Armenise-Harvard Foundation, a foundation at Harvard Medical School (HMS) that supports leading scientists at HMS and at institutions in Italy in the pursuit of scientific discovery in the field of medicine. As an IPPF Patient Educator with the Awareness Program, Ellen has traveled to various universities and professional exhibits to share her diagnosis story with dental students and professionals in order to accelerate pemphigus and pemphigoid (P/P) diagnosis times.

Upon receiving her award, Ellen said, “It wasn’t long ago that I wouldn’t disclose the nature of my disease with people who I didn’t know. I didn’t feel comfortable sharing the fact that I had a chronic illness, let alone such a rare one, and one with such a strange-sounding name. Now I realize how important it is to spread awareness and to do my part to make an impact. With this award, I hope to raise even more awareness of P/P among those in the HMS community and beyond.”

Anna Lane is the IPPF Communications Assistant. She lives in Denver, Colorado, with her family.
In April 2019, biopharmaceutical company Akari Therapeutics announced positive results from its Phase II clinical trial that investigated the use of nomacopan (brand name, Coversin) to treat patients with bullous pemphigoid (BP). These results could provide patients with a new treatment option beyond current treatments, such as corticosteroids. The trial demonstrated nomacopan to be highly effective with an excellent safety profile. Recently IPPF Executive Director Marc Yale sat down with Dr. Paulatsya Joshi to ask him about the trial.

Dr. Joshi is the medical director at Akari Therapeutics in London. Previously, he was the medical director of Wilson Therapeutics AB, London, focusing on ALS (Neurology) and Wilson Disease (Neuro/Gastroenterology). He has also worked as a medical director with BioMarin Pharmaceutical Ltd, London, concentrating on muscular dystrophy. He has held multiple appointments as a clinical research physician, including with Pfizer; served as a clinical development physician; and worked in clinical medicine since 2005. Dr. Joshi holds a CCT with Diploma in Faculty of Pharmaceutical Medicine from Royal College of Physician, London, and a medical degree in anaesthesia from Gujarat University, Civil Hospital, Ahmedabad, India.

When was Akari Therapeutics formed?
Dr. Paul Joshi (PJ): Akari Therapeutics was formed in New York and London (UK) in 2015.

How long have you been at Akari Therapeutics?
PJ: I started working as a Medical Director in November 2017. I am responsible for providing medical leadership for Akari’s BP clinical program.
Why did Akari Therapeutics decide to work on a Phase II clinical trial for BP?  
*PJ:* Akari’s lead investigational compound, nomacopan (Coversin), exhibits dual inhibition of complement C5 and leukotriene B4 (LTB4). There is evidence that both complement system and LTB4 are involved in the pathogenesis (development) of BP, so nomacopan has the potential to treat the disease.

This led the company to conduct pre-clinical studies with Lübeck University, Germany, in 2017 with nomacopan in a disease like BP. Encouraging pre-clinical results led to the initiation of a Phase II clinical trial in mild to moderate BP patients in the Netherlands and Germany in 2018. The trial is ongoing and recruiting.

Is Akari Therapeutic’s novel therapy for BP designed to be steroid-sparing, or will it eliminate the need for steroids altogether?  
*PJ:* It is difficult to comment precisely on the role and impact of this therapy at this early stage of clinical development. On the basis of early clinical data observed in the ongoing study, nomacopan has shown the potential to be a steroid-sparing therapy and also indicated the possibility of eliminating the need for steroids in some patients.

Did the Phase II clinical trial meet all of its objectives and endpoints?  
*PJ:* The ongoing Phase II clinical trial is recruiting patients and is expected to be completed in 2019. The full dataset at the end of the study will allow assessment of whether all objectives and endpoints have been met. However, the data from the first three patients have shown an encouraging picture regarding safety and efficacy endpoints.

How is nomacopan administered to patients, and how often would patients need to take it (daily, weekly, etc.)?  
*PJ:* The investigational compound nomacopan is administered under the skin (subcutaneously). This is like administering insulin under the skin for the treatment of diabetes. Following two injections (12 hours apart) taken on the first day of therapy, patients continue to take a once-daily dose, preferably at the same time each morning.

Are there plans to expand the trial?  
*PJ:* The ongoing Phase II trial is being performed in the Netherlands and Germany, at six sites in total. In the future, the clinical trial program will involve more countries in Europe and sites in the US.

What impact does Akari Therapeutics feel this therapy will have on the lives of patients?  
*PJ:* The current standard of care with corticosteroids is poorly tolerated among the BP patient population who are of advanced age and often have co-morbidities. So, there is a need to develop safer therapies that decrease the reliance on steroids for this patient population. Nomacopan has the potential to decrease the dose of corticosteroids and in some cases to eliminate the requirement for steroids. It is also expected to be safer than steroids and achieve rapid disease control.

Many patients are hospitalized during early stages of treatment with corticosteroids, and nomacopan can minimize this. Patients may also need fewer hospital/clinical visits for dose adjustment of corticosteroids or switching treatment regimens. The possibility of fewer and less severe side effects with nomacopan therapy may improve the quality of life for BP patients.

Additionally, some patients do not like applying a topical treatment by hand to skin lesions and some of the BP lesions (for example on the back) are difficult to reach by hand, too. Nomacopan is given via a once-daily injection under the skin, so it can avoid the need to apply a topical therapy.

How can the IPPF community help Akari Therapeutics in the drug development process?  
*PJ:* Patient involvement and feedback about treatment experience is an integral part of drug development. We encourage the IPPF community to get involved with clinical trials associated with nomacopan to help bring this new therapy to the market.

For more information about clinical trials, visit www.pemphigus.org/research/clinical-trials.

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Marc Yale was diagnosed in 2007 with cicatricial pemphigoid. In 2008, he joined the IPPF as a Peer Health Coach and was promoted to Executive Director in 2016. Marc currently resides in Ventura, California, with his wife Beth and daughter Hannah.
As pemphigus and pemphigoid (P/P) patients, one of the first lessons we learn is that it’s very hard to receive a correct diagnosis. The second thing many of us learn is that medications are expensive.

Historically, Pharmacy Benefit Managers (PBMs) have been hired by private employers, states, and even the federal government to help process medication claims for insurance companies for a small fee. They encourage the use of generic medications, reduce waste, and promote compliance in order to save money. PBMs are also able to buy large volumes of medications to reduce prescription costs and pass these savings on to the consumer. Therefore, it’s reasonable to assume that PBMs would be beneficial to P/P patients by helping them gain access to affordable prescriptions. Unfortunately, this is not the case.

These middlemen have become the administrators of drug plans that negotiate drug prices between manufacturers and insurance plans, and even determine which pharmacies are in-network. They use secret formulas to negotiate in order to drive down prices, and generally state that they cannot share formulas or they wouldn’t be able to negotiate great pricing.

So why are drug prices still so high in the United States? PBMs generate income in a number of ways: by charging fees to manage the drug supply chain; by determining the difference between the amount they charge pharmacies for drugs and the price those pharmacies are allowed to charge customers; and by taking advantage of rebate programs from drug manufacturers. At the end of the day, patients are not seeing the cost savings PBMs are supposed to provide. This also has to do with the fact that 95 percent of the US population’s prescriptions are managed by the three top-leading PBMs. This reduces the motivation to reduce drug prices by removing the competition.

According to a report by Applied Policy, LLC, a health policy and reimbursement consulting firm: *Over the past decade, the role of PBMs in the delivery of healthcare has increased, due to a confluence of*
factors: coverage expansions under both the Medicare Part D prescription drug benefit and the Affordable Care Act, combined with an increase in prescription drug spending that has motivated commercial health plans and self-insured employers to outsource the management of their spending on outpatient prescription drugs (www.appliedpolicy.com).

So, what can patients do about PBMs and the high cost of our prescription medication? First, we can contact our state and federal legislators by phone, mail, email, or in person at their local district offices. We can ask them to support legislation that encourages transparency of drug pricing and how PBMs determine drug pricing. We can encourage lawmakers to remove legislation that keeps a pharmacist from offering you ways to save money. When we buy other products, the prices are clearly marked. We know there are costs to bringing products to market, and high-cost products are usually priced to cover the expenses of research, packaging, development, and the risk of investment. But the price is clear before purchasing. It should be the same with medicine.

Another option is to compare costs from multiple pharmacies to find the lowest price. Since PBMs have the power to negotiate in-network pharmacies, it may be possible that the nearest pharmacy is more expensive due to being out-of-network. We can also consider going to a "big box" pharmacy. Sometimes larger buying power can provide savings. The same is true of asking doctors to write a prescription for 60 or 90 days instead of 30 days, as this may allow patients to save on copays.

Patients can also research medication costs prior to getting a prescription filled by checking websites like GoodRx (www.goodrx.com) before going to the pharmacy. They compare the cash price of pharmacies in a given area. Note: Be sure to verify that the medication listed is in the same form as the one your doctor prescribed (capsules, tablets, etc.). Also, it’s important to be aware that the amount you pay may not go towards your deductible, depending on your insurance plan.

So, what can patients do about PBMs and the high cost of our prescription medication?

It’s always a good idea to ask, “What’s the price if I pay out of pocket instead of using my insurance?” Insurance companies can negotiate prices, but it may actually be higher than paying out of pocket in some cases. It is also possible to ask the pharmacist if a cheaper generic is available, or if coupon cards or discounted programs are available for name brand medications. Many pharmacies also offer their own programs that will help save on prescriptions.

It is my hope that this information is helpful in understanding more about drug pricing and the steps patients can take to reduce prescription costs. The IPPF works with different organizations, including the National Organization for Rare Disorders (NORD) and the American Academy of Dermatology (AAD) to advocate for our community. We’re all in this together.

Becky Strong is the IPPF Outreach Manager. She was diagnosed with PV in 2010 and is currently in remission. She lives in Michigan with her family.

Find other stories and the latest info on the IPPF news site: pempress.com
Did you know that the IPPF offers a variety of free patient services to help you live an active, productive life? These include our Peer Health Coach program, Patient Education Series webinars, local and regional support groups, Find a Doctor map, annual Patient Education Conferences, educational resources, and the IPPF Natural History Study. These are just some of the ways to connect with the pemphigus and pemphigoid (P/P) community.

Peer Health Coaches

The IPPF’s peer health coaches (PHCs) help more than 1,500 patients and caregivers each year. As patients themselves, our specially trained PHCs reduce patient anxiety and uncertainty while providing unbiased disease and treatment knowledge. PHCs engage with the community through emails, phone calls, social media, and in-person support. They work on building relationships with patients and caregivers while providing emotional support. Currently, we have five coaches, all of whom are happy to help.

So far this year, we’ve helped over 400 people! If you have questions about how to manage your disease, need advice, or want someone to listen who understands what you’re 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. Join a webinar to listen, learn, and submit a question. These webinars can be accessed live online or via phone. Webinars are structured to give the guest speaker time to present and then answer incoming questions from the community. All webinars are recorded and can be downloaded from the IPPF website.

This year’s topics have included intravenous immunoglobulin (IVIG), oral care, immunosuppressants, Rituxan® and Genentech’s Access Solutions Program, and oral treatment of P/P. To register for an upcoming webinar or to listen to a past recording, visit www.pemphigus.org.

Local Support Groups

It can be helpful to connect with others who know what you’re going through. Our local support groups provide an in-person setting to 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, including caregivers and family members. There is something about sitting together in the same room with people who really know what you’re going through. Information about upcoming meetings or how to start a group in your area can be found at www.pemphigus.org/events.

Find a Doctor Map

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 an interactive map to help connect you with a physician who is knowledgeable about these diseases. 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 and get directions to their offices. Access the Find a Doctor Map at www.pemphigus.org/find-a-doctor.

We continually add to the list of physicians. If your physician is not on the list or you know of one that should be, please send their information to Becky Strong: becky@pemphigus.org.

Patient Education Conference

Join us from October 11-13, 2019, to celebrate the 25th Anniversary of the IPPF at our annual Patient Education Conference! This year’s conference will be in the city of brotherly love, Philadelphia, PA. Philadelphia has historical charm, is filled with unforgettable museums, a happening nightlife, worshiped sports teams, and a flourishing restaurant scene beyond the famous cheesesteak.

We’ve invited leading bullous disease experts to present on research and trends, educate about disease management, and answer tough questions from patients. The conference is a great opportunity to meet other patients and caregivers while learning more about living—and thriving—with P/P.

The conference kicks off on Friday, October 11, with a Welcome Reception. Saturday will give attendees the opportunity to follow either a pemphigus or pemphigoid learning track. Each session will include panel discussions that encourage questions and interaction with the presenters. Our 25th Anniversary Celebration on Saturday night will include cocktails, dinner, and a casino night! Sunday will highlight personal disease management with workshops on patient-focused themes that are designed to help patients live happier lives. For more information, a full agenda, and registration visit: www.pemphigus.org/philly2019.

Natural History Study

The IPPF Natural History Study is a great way to help make a difference by advancing the science and study of P/P. Launched in 2017, the IPPF Natural History Study is a patient registry sponsored by the National Organization for Rare Disorders and the US Food and Drug Administration. This online data system collects, stores, and retrieves patient data for analysis in research studies. The study is designed to help the medical and research community 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: www.pemphigus.iamrare.org.

Other Resources

IPPF website (www.pemphigus.org): Find 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.

Social media: Connect with the IPPF on Facebook (www.facebook.com/healourskin) and on Twitter and Instagram: @healourskin

RareConnect (www.rareconnect.org): This discussion forum is not run by the IPPF; however, RareConnect is a great place for rare disease patients, families, and patient organizations to connect and develop online communities.
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.

**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.

**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.

**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 with 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.

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All PHCs are pemphigus or pemphigoid patients who have learned how to manage their diseases effectively. They are willing to share their journeys, tips, and tricks. Every coach brings a personal perspective and all of the IPPF resources to support each patient they work with. This support is meant for educational purposes to help members of our community effectively communicate with their doctors and make educated choices about their care.
Finding Strength as Both Doctor and Patient

Kathleena D’Anna

When I was first diagnosed with pemphigus vulgaris (PV), I didn’t have the slightest clue what those strange words meant or how this disease would impact my life. The physician who finally diagnosed me handed me a description of the disease and referred me to another doctor, an expert in PV management.

In the meantime, I waited nearly three months to see a specialist, armed with only a vague report on the medically and statistically significant features of PV. I felt alone and confused, feelings only amplified by descriptions that didn’t relate to me at all—I wasn’t even half the age of the individuals typically affected! I had so many questions. What if they got the diagnosis wrong? What could I eat to help heal the sores? What could I do besides take a handful of pills every day?

It was during one of my many internet searches that I came across the IPPF. I couldn’t believe that there was an entire organization dedicated to patient information, and I immediately took advantage of connecting with a peer health coach (PHC). My PHC was the first person to actually tell me, “It’s okay to be scared, everything is going to be okay.” I will never forget those words. They were the reassurance I had been missing and desperately needed. From there I began to realize that I wasn’t alone, that I didn’t need to figure everything out on my own. There were other people who had been through similar experiences to help guide me through this journey.

As I engaged more within the IPPF community, I realized how important and therapeutic it was to share my personal experiences living with PV. Prior to attending Rare Disease Day with the IPPF, I had never told anyone except my close family that I had an autoimmune disease. I hid it away like a dirty secret because I was afraid of appearing weak or being treated differently. Especially as a student of medicine—we are supposed to treat patients, not be them.

When I finally met the members of the IPPF in person—the individuals whose stories I’d read and advice had given me confidence—I decided that I was done denying that part of myself. I am a doctor and a patient. Having PV has made me the person I am today. Rather than being a weakness, it has given me the strength to be wiser and more empathetic. I will use what I’ve learned to teach others, share what I can in both the patient and the medical communities, continue to raise awareness of PV, and elicit change in how people view medical conditions.

Dr. Kathleena D’Anna is an internal medicine resident at Loma Linda University.
I've been a peer health coach (PHC) with the IPPF since 2012. However, if you had told me back in early 2001 that this is what I would be doing today, I never would have believed you. I had never even heard of pemphigus vulgaris (PV) then, much less known about rare autoimmune diseases.

I've always believed that everything happens for a reason and that no matter how good or bad it is, there is a destiny in the event. When I finally was diagnosed in February 2001, I didn't think, “Why me?” Instead, I thought, “Why not me?” I also couldn't figure out why I thought that! When I reached remission 11 years later in 2012, I was asked by the IPPF to become a PHC.

My journey with PV started in October 2001. A friend and I were out to dinner one night. While we were waiting for the valet to bring us our cars, I felt a tiny bump on my upper back. I asked my friend to look at it and whether it looked like a bite. She thought it did. When I went home, I put some aloe with vitamin E on the bump and covered it with a small bandage. The next day there were two more bumps. In the ensuing weeks, I would find about 10 more bumps. Pretty soon, the bandages weren't large enough to cover them. They grew so big that even a gauze square wasn't enough to cover them. I bought Telfa pads and paper tape, because it turned out I was allergic to adhesive as well. These “bites” kept growing. My upper back was completely covered, it was raw, oozing, and extremely painful. It looked like I had open wounds from being hit by shrapnel.

Clothing hurt. A strand of hair touching my back felt like a razor blade was cutting into me, so I had to cut off all my hair. I couldn't shower because the water hitting my skin hurt. Positioning myself on my mattress was painful and took fifteen minutes. Sleeping was a challenge because of the pain and my skin sticking to the sheets. Three months of misdiagnoses and money spent on the wrong medications prompted anxiety, fear, and anger.

My dermatologist, Dr. David Rish in Beverly Hills, was out of town for the holidays, so I saw three of his colleagues who, month after month, kept diagnosing me without success. When Dr. Rish returned at the beginning of January, he said, “I think I know what you have,” and he sent me to a phlebotomist to have a blood test. The phlebotomist had to make a special phone call to her boss asking what to look for since she had never done that type of blood draw before. Dr. Rish also told me not to go on the internet. Who would listen to that? When I searched for pemphigus, I panicked. I read that there was a five-year mortality rate. Did that mean that I had five years left to live? I went into an immediate emotional dive.

I was finally diagnosed by an associate dean of dermatology at UCLA in February 2002 and was started on 100mg of prednisone. Sadly, this doctor passed away two months after seeing me, and I no longer had a doctor to treat me for this scary condition. Dr. Rish kept refilling my prescription while I went on the hunt for a doctor who could treat me. I found the IPPF online, joined the email discussion group, and went to a local support group meeting. I also met Janet Segall, the founder of the IPPF.

I started seeing the doctor from the support group meeting, and she kept me on prednisone.
had spread from my upper back to my scalp, and then to my mouth. Three or four months passed before my gums started to peel back. I was scared I was going to lose my teeth. Then the blisters started under my tongue and inside my cheek. Eventually, blisters were in my larynx. I sounded like a frog, and I couldn’t swallow without pain. Ensure was my breakfast, lunch, and dinner for a few weeks. To this day, I still have to cut out clothing labels from new clothing as they irritate my skin, and I hardly ever go out in the sun as too much exposure can lead to a disaster.

In the beginning, my dentist said he had vaguely heard of PV. He didn’t know very much about it and didn’t seem interested to learn more. My dental hygienist had never heard of PV either, and I explained it to her. I asked her to be very careful with the instruments. She tried, but there was quite a bit of flinching. I kept educating each new dental hygienist, as they rotated and worked various clinics at once.

Because I was hurting from PV, I rarely went out and cut back on seeing friends or going to temple. I became quite isolated. However, I stayed active online with the PV discussion group, and whenever there was a support group meeting, I attended and helped out.

I attended my first IPPF Patient Education Conference in Los Angeles in 2007, followed by the conference in San Francisco in 2013, and I was very involved with the IPPF whenever I could help out. I have been in remission since September 2012 and have not had an episode since.

I love what I do as a PHC. I remember what it was like for me when I was first diagnosed with PV, so I can empathize with the patients who contact the IPPF. Along with IPPF Executive Director, Marc Yale, I also organize patient support group meetings for Southern California patients, and I regularly give a workshop at the Patient Education Conference on how to de-stress. I feel blessed to be able to help others and give back in service the same kind of support I was given. It helped me survive this rare autoimmune disease. I can’t imagine doing anything else with my life right now. I am blessed to be a part of the excellent IPPF team.

Mei Ling Moore was diagnosed with PV in 2002. She has been a Peer Health Coach with the IPPF since 2012. Along with Marc Yale, she organizes the Southern California support group. Mei Ling lives in West Los Angeles.
It was January 2007, and I was sitting across the desk from the second dermatologist I had seen in five months. For the second time, I was told that my condition was probably "seborrheic something-or-other" and was prescribed an alcohol-based topical steroid that I knew would be painful to apply. I had endured three months of increasingly widespread lesions on my scalp and back, but hadn’t associated those with the bad mouth sores and sloughing of my gums that started the previous summer.

The following week, I was scheduled for a tooth cleaning that I’d put off because I was afraid it would hurt. The poor dental hygienist probably never had performed such a bloody cleaning. When the dentist inspected my mouth, he immediately scheduled me for a biopsy. The result came back positive for pemphigus vulgaris (PV). Lucky me.

Actually, I was lucky—I lived within a short train ride of Manhattan and Langone Health at New York University (NYU), which meant I had access to medical professionals with extensive experience with PV. Even luckier, in early March of 2007 I came under the care of Dr. Jean-Claude Bystryn, one of the world’s premier pemphigus experts. Dr. Bystryn treated me until shortly before his death in 2010.

I was diagnosed with PV, was the patient of a top medical professional, had begun to manage my disease with corticosteroids, and had an extraordinarily supportive caregiver in my wife. I wasn’t even aware at the time that I was missing a crucial part of what I needed in my battle with my disease: I didn’t have the slightest clue about how to live with PV day-to-day.

That’s when the IPPF came into the picture. Much of my career was spent associated in one way or another
with the medical profession, which has perhaps made locating and comprehending detailed information about causes, treatments, side effects, insurance issues, etc., a bit easier for me than for some patients. My internet searches had turned up a ton of technical information and research papers about autoimmune blistering diseases, but not much about what it’s like to work, play, travel, or simply get out to a decent restaurant while dealing with stares and questions (and some well-intended but really bad advice) from friends and strangers. I felt alone. I knew there must be others out there who were struggling like I was, but until I found the IPPF website, I didn’t know how to connect with them. From my first tentative emails with Mei Ling Moore and Marc Yale, I knew: there were people who understood.

Of course, the IPPF website itself contains much information about the various forms of pemphigus and pemphigoid (P/P) as well as the services the IPPF provides. However, it has been the interaction with fellow patients through the peer health coaches, support groups, and the annual Patient Education Conferences, that have proven the most valuable to me. My work schedule kept me from attending a Patient Education Conference until 2014, when I traveled to Chicago and was able to meet so many people I had already encountered either through the IPPF website or various social media outlets. It was in Chicago that I learned of the potential of rituximab as a treatment option and attended meetings on topics such as relaxation techniques, dietary considerations, and the Awareness Ambassador Program (the outreach effort the IPPF put together to reduce the time gap between first symptoms and diagnosis). Just spending time with people who knew exactly what I was going through, who knew the instantaneous fear and rage that goes along with each new lesion, who were discovering how to find the shady spots at high noon, was an amazing comfort.

In Chicago, I not only signed on to help with the Awareness Program, but I also joined the Patient Registry, which has now been succeeded by the Natural History Study. Since then, I’ve attended Patient Education Conferences in New York (including a very chilly Mets-Yankees game!), Newport Beach, and Durham (where I re-established old friendships and met newer members of the P/P community). I’ve also met with members of my local support group; volunteered to help staff the IPPF booth at the Greater New York Dental Meeting in 2017 and 2018; provided P/P information to dozens of local dentists; and most recently advocated for the IPPF and supported legislation as part of Rare Disease Week on Capitol Hill.

I’m not writing all this to tell you what a good guy and solid citizen I am. I’m not a “joiner” by nature, and it surprises me that I’ve become involved as much as I have. The IPPF has provided such a solid foundation of support, both practical and intangible, to me over the years that I truly feel a part of the family. That’s what has instilled in me the impulse to roll up my sleeves and help out.

My PV has been in remission (no flares and no medication) for more than three years, but the IPPF continues to be an important part of my life. The Patient Education Series webinars help keep me up-to-date, and I look forward to each new issue of the Quarterly. I have already set aside time for the Patient Education Conference in Philadelphia this October.

Dealing with this ugly group of diseases is nothing any of us would have chosen. Make no mistake: I wish there wasn’t a need for this organization. I wish it had never been necessary to meet the patients, caregivers, and staff I’ve come to love and admire and whose friendship and commitment mean so much to me. But I am grateful every single day for having the opportunity to share this journey with them.

Fred Wish is a PV patient who lives at the Jersey shore. He retired from full time work in 2010 and owns a writing and editorial service company with his wife, Loretta. He enjoys being a member of a classic rock band, plays a passably competent game of poker, and looks forward to spoiling his two-year-old grandson at every chance.

The IPPF has provided such a solid foundation of support, both practical and intangible, to me over the years that I truly feel a part of the family.
A Look Back at UNC Dental Day

Ryan Stitt

On October 12, 2018, I participated in the IPPF Dental Day as part of the 2018 Patient Education Conference. Dental Day was hosted at the UNC Adams School of Dentistry by Drs. Donna Culton and Ricardo Padilla. As a dental student, I found this to be by far the most exciting and enriching experience of my dental school education to date.

Pemphigus and pemphigoid (P/P) patients traveled from different parts of the world to attend the conference. During the Dental Day event, dental and dental hygiene students were put into groups under the supervision of UNC faculty. We performed thorough extraoral (head and neck) and intraoral examinations on P/P patients. We discussed their diseases as they related to oral symptoms and oral care, and learned about the personal implications of living with P/P. Students provided patients with oral hygiene instructions and suggested products and techniques to aid in disease management. We also encouraged them to establish a dental home if they did not already have one.

As students, we learned about using the Nikolsky sign in the oral mucosa to aid in the diagnosis of P/P. In order to help dental students better understand P/P, patients allowed us to poke and prod their oral tissues. The initial examination gave us clues about the type of autoimmune disease that the patient might have, though definitive testing would still be required to confirm a diagnosis.

For me, one particular interview with a patient was impactful. She informed me that she lived in a town where access to medical care is limited. She explained that for the majority of her life, she had no idea what her disease was because pemphigus is such a rare disease, and she was delayed in being diagnosed. The conversation filled me with a feeling of purpose and provided an understanding of what it may be like to treat patients as a dentist specializing in oral disease diagnosis.

Dental Day was a learning experience for both students and patients. The students who participated were fortunate to perform clinical examinations on P/P patients. Patients were given the opportunity to teach future healthcare providers about their autoimmune conditions. I believe that these types of extracurricular experiences make one’s dental school education truly amazing.

I want to acknowledge the hard work of the faculty and staff for hosting the event at our dental school. I cannot overemphasize what this wonderful experience has given me as a dental student. I am extremely grateful that I was able to meet so many P/P patients and learn firsthand about what it’s like to be afflicted with this type of autoimmune disease. I’d also like to thank the patients who participated and allowed us to learn more about their conditions. Since P/P are such rare and interesting diseases to study, I am hoping to attend the upcoming 2019 Patient Education Conference in Philadelphia in order to continue learning about the latest P/P information and disease management.

Ryan Stitt is a third-year dental student at the UNC Adams School of Dentistry. He enjoys treating patients in clinic and participating in group-based extracurricular activities. In his free time, Ryan crafts zip lines at his home and practices playing the guitar.
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The Quarterly is made possible in part by a grant from Incyte.

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