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Message from the Executive Director

As summer has passed and we’ve moved into fall, I can’t help but reflect on how much the IPPF has changed in the 11 years since I first discovered this community. From the time I was diagnosed in 2007, the Foundation has more local support groups across the country, enlisted the help of over 80 Awareness Ambassadors banding together to spread local awareness, added more than 200 physicians to its referral list, and implemented an online physician map (www.pemphigus.org/find-a-doc) to provide even greater access to care.

Janet Segall founded the IPPF nearly 25 years ago, hoping to make a difference in the lives of those affected by pemphigus and pemphigoid (P/P). Through her efforts and the commitment of so many, the IPPF community is stronger today than ever before! The IPPF was there when I needed it the most, and we’re here for you now. You don’t have to make this journey alone. Our community has your back, and we will support you.

I am inspired by and would like to thank all who have volunteered with the IPPF over the past year. You have provided immeasurable hope to patients and caregivers with your dedication to our mission. Through our common bond, we can solve the challenges we face, such as accelerating drug development and research for new treatments, creating physician awareness to reduce diagnosis time, and eliminating the stigma that comes with having a rare disease. Our community provides support for one another so we don’t feel so alone.

The Fall, 2018 issue of the Quarterly shows us all what being a part of the IPPF family is all about, and I encourage you to get involved. Become an advocate or an ambassador, attend a local support group, or join the IPPF Natural History Study so we can learn more about these diseases. The IPPF community is the thread that connects us. Together, we can build on our collective strengths, mobilize our efforts, work together as a team, create balance in our lives, and HEAL OUR SKIN!

Gratefully,

Marc Yale
IPPF Executive Director and MMP Patient
marc@pemphigus.org
Rituxan Receives FDA Approval to Treat Pemphigus Vulgaris

On Thursday, June 7th, the FDA approved Rituxan for the treatment of adults with moderate to severe pemphigus vulgaris (PV).

Rituxan is the first biologic therapy approved by the FDA for PV and the first major advancement in the treatment of PV in more than 60 years. The FDA previously granted Priority Review, Breakthrough Therapy Designation and Orphan Drug Designation to Rituxan for the treatment of PV. With this decision, Rituxan is now approved to treat four autoimmune diseases.

“It is our hope that this announcement will open the door to approval for other indications in our diseases and usher in a renewed focus on available treatments,” said Marc Yale, Executive Director of the International Pemphigus & Pemphigoid Foundation.

The FDA approval is based on data from the Ritux 3 trial, a Roche-supported, randomized, controlled trial conducted in France that used Roche-manufactured, European Union (EU)-approved rituximab product as the clinical trial material. The study compared the Ritux 3 regimen (EU-approved rituximab product plus short-term corticosteroids [CS]) to CS alone as a first-line treatment in patients with newly diagnosed, moderate to severe pemphigus. The primary endpoint of the study was complete remission at month 24 without the use of steroids for two or more months. (Complete remission defined as complete epithelialization and absence of new and/or established lesions.)

Results of the study showed that 90 percent of PV patients treated with the Ritux 3 regimen met the endpoint, compared to 28 percent of PV patients treated with CS alone. These results supported the efficacy of Rituxan in treating patients with moderate to severe PV, while tapering off of CS therapy. These results were published in The Lancet in March 2017.

An international panel of experts called the International Bullous Disease Consensus Group recently provided new recommendations on the diagnosis and management of pemphigus in the Journal of the American Academy of Dermatology. Based on existing European treatment guidelines, a Delphi survey process was used to help achieve international expert consensus. The consensus includes the recommendation to use an anti-CD20 monoclonal antibody (Rituxan) and corticosteroids as first line therapy options for moderate to severe pemphigus.

The Role of the IPPF

The IPPF aims to serve as a primary source of information for you regarding this approved treatment and is available to help answer your questions in the upcoming months. If you are considering Rituxan as a potential therapy, please consult your healthcare provider. Inform them of your medical history, and ask about the potential side effects.

The IPPF’s Peer Health Coaches (PHC) 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. You can find our PHCs engaging the community through social media, emails, phone calls, and in-person support. The goal of our PHC program is to ensure we help every person who needs assistance in the shortest amount of time possible.

Genentech Access Solutions

Genentech is the drug company that produces Rituxan (rituximab). Genentech Access Solutions is a resource for people considering Rituxan as a treatment option. It may be worth contacting Access Solutions directly regardless of whether or not you have health insurance.

Access Solutions may be able to help by:
• Checking your insurance coverage and costs
• Helping you find ways to pay for your medicine
• Working to get your medicine to you

Visit Access Solutions to learn more: www.genentech-access.com
Bertilimumab Granted Fast Track Designation for the Treatment of Bullous Pemphigoid

Immune Pharmaceuticals, Inc., a biopharmaceutical company developing novel therapeutic agents for the treatment of immunologic and inflammatory diseases, announced on September 11, 2018, that the US Food and Drug Administration (FDA) has granted Fast Track designation to bertilimumab for the treatment of bullous pemphigoid.

“I am truly grateful that the FDA has granted Fast Track designation to bertilimumab for the treatment of bullous pemphigoid. This important achievement follows the recent granting of Orphan Drug Designation in both the United States and Europe, which together demonstrate the regulatory affairs momentum our team has achieved,” commented Immune’s Interim Chief Executive Officer, Tony Fiorino, MD, PhD. “There is no doubt that bertilimumab development will benefit from the opportunity to have more frequent contact with the FDA, particularly now, as we move forward with a new manufacturing process and plan for a phase 2/3 pivotal study in bullous pemphigoid.”

The FDA’s Fast Track program is designed to facilitate the development and expedite the review of drugs to treat serious conditions that are unmet medical needs. Fast Track designation enables more frequent interactions with the FDA in order to shorten the development and review process, and may include potential eligibility for Accelerated Approval, Priority Review and Rolling Review.

Syntimmune Announces Positive Preliminary Results from Clinical Proof-of-Concept Trial of SYNT001 in Pemphigus Vulgaris and Foliaceus

Syntimmune, Inc., a clinical-stage biotechnology company developing antibody therapeutics targeting FcRn, announced positive preliminary results from its Phase 1b proof-of-concept trial of SYNT001 in patients with pemphigus vulgaris and pemphigus foliaceus. The data showed clinically meaningful benefit of SYNT001, with a favorable safety and tolerability profile similar to that observed in the Phase 1a study.

“There remains a clear unmet need for a safe and fast-acting treatment for patients with pemphigus, who face serious symptoms and complications associated with their disease,” said Donna Culton, MD, PhD, an assistant professor at the University of North Carolina School of Medicine. Culton presented preliminary results of the Phase 1b study at the International Investigative Dermatology conference held on May 16-19, 2018 in Orlando, FL. “These preliminary data demonstrate safety as well as a rapid reduction in PDAI scores and lowering of IgG levels with treatment of SYNT001, which support further studies of this drug as a potential new therapeutic option,” Culton said.

Results from First Cohort

Primary endpoint analysis revealed SYNT001 to be well tolerated in treated patients, with all study drug-related adverse events (AEs) characterized as mild or moderate. No severe or serious study drug-related AEs were reported.

The secondary endpoint measures showed a reduction in mean PDAI score from severe to moderate, with clinical effect persisting beyond the treatment period. Rapid and clinically meaningful reductions in pharmacodynamic biomarkers were observed in all patients. At nadir, mean total IgG levels were reduced by 59% (day 30), mean CIC levels were reduced by 50% (day 33), mean anti-DSG1 levels were reduced by 22% (day 14) and mean anti-DSG3 levels were reduced by 24% (day 33).

“We believe that effective reduction in PDAI scores at this lowest dose indicates the potential for a greater magnitude and duration of response at higher doses. In individual patients, we saw reductions of up to 67% in total IgG, 71% in CIC, 65% in anti-DSG1 and 61% in anti-DSG3. These results strengthen our conviction that reducing pathogenic autoantibodies and blocking key inflammatory functions of FcRn may offer an innovative approach to treat pemphigus and could give rise to therapeutic benefits in a wide range of autoimmune diseases that are similarly mediated,” said Jean-Paul Kress, M.D., president and CEO of Syntimmune.
Aimee Payne and Nicola Mason Receive NIH Award

TRANSFORMATIVE RESEARCH AWARD WILL SUPPORT FURTHER PEMPHIGUS RESEARCH

Nicola J. Mason, BVetMed, PhD, associate professor of Medicine and Pathobiology at the School of Veterinary Medicine at the University of Pennsylvania, and Aimee S. Payne, MD, PhD, the Albert M. Kligman Associate Professor of Dermatology at the Perelman School of Medicine at the University of Pennsylvania, have received the prestigious NIH Director’s Transformative Research Award. The award is part of the NIH Common Fund’s High-Risk, High-Reward Research program, which was established to accelerate the pace of biomedical discoveries by supporting exceptionally creative scientists with highly innovative research.

Autoimmunity occurs when the body's immune system mistakenly attacks normal tissues, thereby causing diseases such as rheumatoid arthritis, systemic lupus, and type 1 diabetes. According to the Autoimmune Disease Research Center at John Hopkins, at least ten million Americans suffer from the more than eighty illnesses caused by autoimmunity. Under the grant, Mason and Payne are looking to evaluate a genetically engineered cell-based therapy approach to treat pet dogs with naturally occurring autoimmune skin disease known as pemphigus. Dogs are one of the few other species to develop pemphigus naturally and the condition mirrors pemphigus in human patients. Evaluation of this approach to treat pet dogs with this debilitating disease may ultimately lead to breakthrough therapies for humans.

"The successful treatment of autoimmunity in the family dog using this unique approach would not only be a breakthrough in veterinary medicine," said Mason, "but could also change the way autoimmune disease is treated in humans. We believe that this work may facilitate the translation of cellular immunotherapies for a broad range of canine and human diseases, including autoimmunity, transplant rejection, infectious disease and cancer."

Mason and Payne will continue to focus on their novel gene-engineered chimeric autoantibody receptor T cell (CAART) immunotherapy and its potential to cause lasting remission of antibody-mediated disease.

"Our study of CAART immunotherapy in companion dogs with naturally occurring autoimmune disease will be synergistic with our efforts to develop similar human therapies," said Payne. "By comparing how these complex cellular immunotherapies work in dogs versus humans, we will better understand how to engineer and deliver these therapies to potentially cure disease."

Mason, who earned her BVetMed from the University of London, and her PhD from the University of Pennsylvania, is a board-certified veterinary internist and immunologist. For the past ten years, she has been actively involved in evaluating the immunological responses of immune-based therapies in client-owned dogs suffering from lymphoma, osteosarcoma, and hemangiosarcoma. Mason’s research laboratory is currently developing CAR-T cell therapies for dogs with B cell lymphoma, and she serves as the PI and lead investigator on the first clinical trial evaluating CAR-T cell therapies in dogs.
Awareness Ambassadors

Awareness Ambassadors are International Pemphigus & Pemphigoid Foundation community members (patients, friends, family, healthcare providers, etc.) who band together to spread awareness of pemphigus and pemphigoid (P/P) locally.

Their goal is to help P/P patients receive a diagnosis faster. They do this by putting P/P “on the radar” of dental and medical professionals.

Make a Difference

Ambassadors are engaged in their communities, participating in activities such as:

- Distributing educational materials to dental providers
- Spreading awareness of P/P on social media
- Helping the IPPF promote specific events and days of action

Easy to Participate

1. Request info: http://pemphig.us/ambassadors
2. Take a short, online, self-paced training
3. Register and choose your activities!

The IPPF Awareness Program is made possible by the generous funding of the Sy Syms Foundation and the Unger family.
In my opinion, we are living in an era of “super-specialization.” The days of family doctors making house calls are gone. Medical school graduates do internships, specialty residencies, and fellowships in order to become specialists in particular areas of medicine. Do they learn all (or most) of the basics? Yes. Do they remember those basics and utilize this knowledge? In my experience, while specialists may remember the basics, some are so focused on their areas of specialization that they may not look at each other’s available notes or talk with each other. Such specialists may be missing the opportunity to treat their patients holistically.

For a healthy person without any major medical issues, a 15- or 20-minute physical exam may be sufficient. But what about patients who have several comorbid medical diagnoses and/or more than one chronic disease or aging issue? My experience has been that rare illnesses typically need to be handled by specialists. So if a patient has multiple conditions that may require multiple specialists, who becomes the captain of the ship? Who is looking at all the specialty information and running the show? Puzzle pieces are supposed to fit together, but who has access to all the information as well as the motivation, knowledge, and time to put it all together?

This leads to another important question: which of your doctors really know and understand you and your unique situation? As a clinical psychologist, I recognize the need for mental health professionals to at least be tangentially part of “the team.” In fact, it still bewilders me that very few MDs and DOs employ a mental health professional or refer chronic or seriously ill patients as a routine part of patient care. This normally only becomes part of the protocol for cancer or serious heart disease. Before the 1950s people did not see dental professionals annually; they went when a tooth became painful and likely needed to be pulled. Nothing was proactive. Dentistry has come a long way since then. Why has the mental health field not kept pace?
Over the last few decades, I believe that the stigma in seeking mental health care has become less of an issue. However, I continue to advocate that annual mental health screenings be as much a part of patient treatment as annual physicals, Pap tests, blood work, mammograms, visual screenings, and dental exams. Keeping on top of mental health may keep sadness from becoming major depression, or anxiety from becoming a panic disorder. Small problems may easily become a downward spiral and have a domino effect. Therapists, social workers, and psychologists listen to subtle difficulties, environmental factors, and sleep/wake patterns. They listen to the whole person and do not focus on just one or two specific areas.

An annual mental health screening could include an initial assessment and possible follow-up session. The patient would then know they have been heard by someone trained to listen to them as a whole person. The patient would be told how they have been perceived and if is recommended to continue therapy, or if it is advisable for them to speak to their physician about medication. Patients may be given suggestions on how to better cope with daily activities. Strengths and weaknesses will be identified, and advice will be offered regarding ways to best work from their strengths. The patient has the option to return after one year to be reevaluated by the same mental health professional to see if circumstances have changed. If the person is further challenged in the course of the year, they can always make another appointment. Reality checks can be done, and other courses of action can be recommended as needed.

Psychology and mental health are not independent from physical health. Mental and physical health are part of the whole person, yet as medicine has evolved into an era of super-specialization that adheres to strict diagnostic restrictions and the justification of face-to-face time to insurance companies, this concept is becoming more rare. I believe that it is important to keep all of your doctors informed about care, treatments, and medications since the information may not be accessible or shared among various professionals.

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.
It seems impossible that months of planning and anticipation for the 2018 IPPF Patient Education Conference are over. This year’s conference was held in Durham, NC, and was hosted by Donna Culton, MD, dermatologist and Assistant Professor at the University of North Carolina (UNC), and Ricardo Padilla, DDS, Associate Professor and Director of Oral and Maxillofacial Pathology Graduate Program at UNC. Dr. Padilla and Dr. Culton set a high bar for this conference. Guests stayed at the “Mansion on the Hill” DoubleTree by Hilton at Research Triangle Park.

Upon arrival, attendees were greeted by white rocking chairs, porch swings, and a sense of belonging. The hotel provided a relaxing environment for conference activities. The conference was an amazing opportunity for patients and their support systems to not only have direct access to IPPF staff, but also some of the leading minds who treat pemphigus and pemphigoid.

This year, the conference kicked off with a special “Dental Day” at UNC School of Dentistry. Attendees were welcomed by UNC staff and students at the Chapel Hill campus. Dr. Padilla welcomed everyone and introduced me as the morning’s first speaker. I shared my journey with pemphigus vulgaris (PV) and encouraged everyone to find their voice and strength after being diagnosed with pemphigus or pemphigoid (P/P).

UNC dental hygienists Jennifer Brame, Elizabeth Kornegay, and Jennifer Harmon then spoke about oral hygiene and how to use different products when patients have oral lesions. Next, Dr. Katherine Ciarocca (UNC) and Dr. Padilla discussed the oral side effects of treatments used in P/P. After lunch, attendees were given the opportunity to have an oral cancer screening and a one-on-one dental examination that included self-care techniques. The afternoon also included a discussion panel with me and Dr. Si Om Lim (UNC).

Upon returning to the conference hotel, attendees were invited to a welcome reception on the veranda. It was a perfect ending to the first day of the conference.

After breakfast and receiving their conference gift bags, attendees began day two of the conference with IPPF Executive Director Marc Yale’s welcome and a video from Senator G.K. Butterfield, 1st District, NC, Rare Disease Congressional Caucus Co-Chair.

The first presentation of the day was Kenny Metcalf, a PV patient from California. Kenny shared his emotional journey that led to his career as an Elton John tribute artist. Attendees then had the opportunity to see Kenny perform later that evening during the IPPF Awards Dinner. Kenny’s story highlighted the struggles that many of us have experienced with P/P.

This year, the conference featured separate learning tracks for pemphigus and pemphigoid. This allowed attendees to focus on the information that was most relevant to them. Sessions were specific to each disease and provided excellent information. The pemphigoid session was moderated by Marc Yale and Dr. Padilla. Dr. Janet Fairley (University of Iowa) gave a great introduction to the disease. Dr. William Huang (Wake Forest University) then discussed topical treatments.
used in pemphigoid before Dr. Russell Hall (Duke University) covered steroids and immunosuppressants.

The pemphigus session was moderated by Dr. Culton and began with an overview of pemphigus by Dr. Grant Anhalt (Johns Hopkins). Dr. David Woodley (University of Southern California) then discussed topical treatments used in pemphigus, and Dr. Adela Rambi Cardones (Duke University) discussed steroids and immunosuppressants.

After a short break, attendees were treated to disease-specific uses of Rituxan® and intravenous immunoglobulin (IVIG) therapy in pemphigus or pemphigoid. Dr. Ron Feldman (Emory University) and Dr. Huang led the discussion on pemphigoid, while Dr. Anhalt and Dr. Culton led the discussion on pemphigus.

On Saturday afternoon, Dr. Luis Diaz (UNC) shared 40 years of research in his keynote address, “Lessons from Endemic Pemphigus Foliaceus.” Dr. Diaz has been involved with the IPPF from its inception. Though primarily based at UNC, Chapel Hill, he has also conducted pemphigus research in Brazil for over 30 years. His research has included disclosing the immunopathological mechanisms operating in PV and pemphigus foliaceus (PF). Dr. Diaz is a true gem in our community.

After the keynote, there was an oral care discussion panel with Dr. Padilla, Dr. David Sirois (NYU), Dr. Nancy Burkhart (Texas A&M), and Dr. Joel Laudenbach (Carolinias Center for Oral Health). Attendees then attended lectures on the genetics of pemphigus and pemphigoid by Dr. Animesh Sinha (University of Buffalo) and “Future Trials of Targeted Therapies in Pemphigus” with Dr. Hall and Dr. Fairley. Later, Dr. Culton introduced Jeff Weisgerber, a PV patient from North Carolina who has participated in two different clinical trials. Jeff shared his experience with the hope of breaking down barriers relieving potential fears patients might have about study participation. Marc Yale then discussed the IPPF Natural History Study and the importance of patient participation. Dr. Brittney Schultz (University of Minnesota) followed Jeff by discussing quality of life issues with P/P. Kate Frantz, IPPF Awareness Director, held an on-the-spot Awareness Ambassador training before Genentech representatives Jocelyn Ashford, Esther Newman, Kristine Amor Surla, and Kenia Carrillo Perez gave a great overview of Genentech Access Solutions and what they can offer to patients with P/P.

Following the day’s sessions, attendees had just enough time to change before the evening’s program. During the cocktail hour many hoots, howls, and laughs were had at the photo booth. The evening’s main event was the IPPF Awards Dinner, where individuals were recognized for their extraordinary service to the IPPF community. The highlight of the evening was Kenny Metcalf performing as Elton John. When Kenny entered the room, it was as if Elton John from the 1970s had arrived. He sat down at the piano and spoke to the crowd in a British accent, played the piano, and sang. The entire room couldn’t help but swing to the music and sing along. Many of those in attendance showed off their best moves on the dance floor. After a long day of learning, it was the perfect way for attendees to relax with new friends.

Marc Yale opened Sunday by introducing an extraor-
social media to create his legacy and use it as a way to reach others with our diseases. Dr. Annette Czernik (Mt. Sinai Hospital, NY) and New York/Tri-State Support Group Leader Esther Nelson then shared an open discussion about the importance of being an informed patient and the doctor-patient relationship. The first morning session ended with a panel discussion led by IPPF Peer Health Coaches Mei Ling Moore, Rudy Soto, and Janet Segall.

After a quick break, attendees had the choice to attend a variety of workshops throughout the morning. These included “Infections in Pemphigus and Pemphigoid” with Dr. Cardones; “Ocular Disease” with Dr. Julie Skaggs (UNC Chapel Hill); “Drug Development” with Dr. David Rubenstein (UNC Chapel Hill); “Oral Care & Maintenance” with Dr. Nancy Burkhart; “Nutrition” with Kelly Calabrese (PV Patient, Optimal Wellness Solutions); “Women’s Health Issues with P/P” with Dr. Alexis Dieter (UNC Chapel Hill); “North Carolina Rare Disease Advisory Council” with Sharon King (North Carolina Rare Disease Advisory Council) and Tara J. Brit (Associate Chair, Rare Disease Advisory Institute, UNC School of Medicine); “Stress Management” with Mei Ling Moore (IPPF); “Mental Health Issues” with Lynne Mitchell (MES, MEd, RSW, Toronto, Canada); “Wound Care” with Dr. David Woodley; “Men’s Issues with Pemphigoid Disease” with Dr. Ron Feldman; and “Caregiving” with Janet Segall (IPPF).

After the morning sessions, Marc Yale gave his closing remarks.

As the conference ended, it was time to say goodbye to old and new friends. Many new support connections were made, and it truly is a blessing to be part of such an amazing event. The openness of doctors and healthcare providers really gave patients and caregivers access to some of the greatest minds studying these diseases. While we only had a brief time together, it felt like the relationships created will last a lifetime—there is something about talking with somebody “who just gets it.” We hope everyone that attended the conference carries the positive messages with them and knows that we’re all in this together.

IPPF Awards Dinner

The IPPF hosts an Awards Dinner to honor those whose service to our community has made a significant impact over the previous year. It’s a great opportunity for all those affected by pemphigus and pemphigoid to come together in celebration of each other.

Congratulations to our 2018 Award Winners:

LIFETIME ACHIEVEMENT AWARD
Dr. Luis A. Diaz

FOUNDER’S AWARD
Dr. Grant Anhalt

DOCTOR OF THE YEAR
Dr. Donna Culton

DENTAL PROFESSIONAL OF THE YEAR
Dr. Joel Laudenbach

BRIGHT STAR AWARD
Patrick Dunn

STAR AWARD: EDUCATION
Ellen Levine

STAR AWARD: OUTREACH
Iva Rauh

STAR AWARD: PATIENT SUPPORT
Esther Nelson

Becky Strong is a PV patient and the IPPF Outreach Manager. She was diagnosed in 2010 and is currently in remission. She lives in Michigan with her husband Tim and her young family.
This year I attended the 21st Annual IPPF Patient Conference for the first time, and it was one of the most heartfelt, profound, and awe-inspiring experiences. It was unforgettable to be part of a family of individuals from all over the country, Canada, and the Dominican Republic who know, live, and understand the trials and tribulations of this very devastating disease. There were tears and there was laughter.

Patient stories shared by Kenny Metcalf, Elton John tribute and pemphigus patient; Porter Stephens, pemphigus vulgaris (PV) patient; and Esther Nelson, IPPF Tri-State NY Support Group Leader, brought home a sense of well-being to remind us we are not alone in this very isolating illness. I was honored to be given the opportunity to present on my expertise in nutrition. Attendees seemed to appreciate learning about recommended foods to eat and foods to avoid and about detoxification home remedies to counter the side effects of various drug treatments.

Marc Yale and his incredible staff organized a five-star conference with informative sessions where we could learn from doctors about the different issues of pemphigus and pemphigoid. The conference exhibitors were very informative about options for different drug treatments. The hotel staff, especially the banquet department, were attentive, fed us well, and made the experience even more enjoyable. Kenny Metcalf rocked the house during the awards presentation; he is an exact replica of Elton John.

For those on the fence about joining us next year: come. For me, the greatest aspect of the entire weekend was talking with others who are experiencing the same day-to-day trials. Speaking with Daphne, Lisa Ann, Joei, Shauna, and so many others gave me a sense of hope for all of us. If you can travel and are not in severe pain, I highly recommend attending this incredible conference where there is a family of friends and a support system. They will be there with open arms. Thank you, Marc, and your team for helping me get well. I truly appreciate everything you have done!

Kelly J. Calabrese, MS, CCN resides in Colorado Springs, CO. She has been a patient since June 2017 with PV and has been in remission since December 2017. She is a contributing writer for the Quarterly and writes on health, wellness, fitness, and nutrition.
Fundraising: NOT INTIMIDATING ANYMORE

Susie Golda

My husband, Tony, is a pemphigus vulgaris (PV) patient, and we found ourselves in a tough spot last year. After 18 months of conventional treatments of prednisone and CellCept® we discovered they weren’t controlling his disease. His doctor then said it was time for intravenous immunoglobulin (IVIG) and Rituxan® infusions. We had learned about these treatments a few months prior to the appointment at the IPPF Annual Patient Conference. Knowing this was his next option for treatment and being unsure if our insurance would approve these treatments, we decided to hold a fundraiser in preparation of the expenses.

The idea of holding a fundraiser was overwhelming at first. We needed to determine how to make the fundraiser successful through planning the who, what, when, and where details (including food options). First, we needed to come up with an estimated head count and start looking for a location. We spoke to every American Legion, VFW hall, park district, and forest preserve in the area and decided our best option was with our local park district. They had a large pavilion for shade, a shelter in case of bad weather, plenty of parking, electricity, and a nice park for the kids. After picking the location, the real planning began.

We made a flyer with Tony’s picture, a story about him and his battle with PV, a short explanation of the disease, and the event details. We also added a list of items we needed in case someone preferred to donate them. No donation was turned away. We needed to figure out activities for the event and how to get people involved. We never expected what happened next. We passed out flyers to a couple of family members and made a list of places we wanted to visit to ask for donations. I will admit that it felt strange the first time I visited a business and told Tony’s story to the manager. They were strangers, after all, and I was telling a very personal story. I never expected the manager of the first business I visited to not only donate gift cards for
his grocery store, but to pull out money from his own wallet to donate. It made me cry. That initial visit felt like the ice breaker. It was amazing to see how generous and kind people were.

We started out hoping to collect enough items to make a few raffle baskets and ended up with way more than we ever imagined due to the generosity of the community businesses and individual donors. We expected to be turned away at some of the places we visited, but instead we were welcomed with understanding and compassion. We visited coffee shops, grocery stores, restaurants, bakeries, hardware stores, ice cream shops, fast food restaurants, flooring companies, and dental offices. We expected hesitation from potential donors only to find out that people couldn’t help enough.

We wanted to keep the menu at the fundraiser simple and to serve something that everyone would enjoy. From there, “Tacos for Tony” was born. Admission to the fundraiser was $20 for adults and $10 for kids, which included all-you-can eat food, drinks, and dessert. We sold raffle tickets and held a bean bag tournament. To our amazement, every single thing we had at the event was donated, including food, drinks, paper products, raffle baskets, and raffle items. It all started with a simple story about Tony’s disease and raising awareness about PV.

A couple of months after the event we decided to host a fundraiser for the IPPF as a thank you for being so supportive of our family, their hard work, their dedication to helping others with this terrible disease, and for searching to find a cure. We looked back through our notes of places we contacted while looking for a location for Tony’s event and one stood out. It was a pizzeria in a neighboring town that hosts fundraisers during the week for various causes. It was the perfect place to host the fundraiser. Our guests could eat, enjoy each other’s company, and support a good cause at the same time. The restaurant’s plan was simple: pick a date and have attendees make a reservation. They offered their party room for the evening and donated 40 percent of each bill to the IPPF. They couldn’t have made it simpler for us. We didn’t need to charge for admission because the more guests ordered, the more the restaurant donated. It was a win-win situation.

Every attendee received a raffle ticket for door prizes that were donated by local businesses. The fundraiser took place in October, so we made table centerpieces out of glass pumpkins that were wearing orange IPPF sunglasses. Each table had a candle that could be taken home as well as a decorated photo frame that said, “Thank you for supporting the IPPF.” Guests were able to take pictures with the frames while wearing orange IPPF sunglasses. We ended up raising almost $700 for the IPPF! We’re planning another fundraiser at the same location this month.

Susie Golda is an office manager for an Illinois land surveying company and is an animal ambassador with their therapy dog. Her husband, Tony, is a PV patient and a lead cook for Sunrise Senior Living. He was diagnosed in 2015 and just completed treatments of rituximab and IVIG. The Goldas live in Illinois with their two children and the family Goldendoodle.
The Gift of Pemphigus Vulgaris

Staci White

One morning, after finishing my workout, I began strategizing ways to convince my doctor that two years into remission was the perfect time for me to get the butterfly tattoo I wanted. Butterflies now have a special place in my heart as a simple, yet extraordinary, symbol of renewal; of the necessary challenges in life that mold you into the person you should become. My plan is to place it on the inside of my left wrist as a reminder of what I’ve overcome and the beauty that awaited me on the other side.

As I tried to determine the angle I would use to secure my doctor’s blessing for this tattoo (to know my doctor is to understand why I needed to be prepared), the first thing that came to mind was that the tattoo was an opportunity to take something back that pemphigus vulgaris (PV) stole from me. That is the nature of chronic illness, isn’t it? It took from me my perceived control of my body, months from my life as I recovered, and so much more.

The madness was that I soon began thinking how much PV actually had given to me. This startled me a bit. But as I let it linger, I realized that PV had given much more than it had taken from me. Dammit! Who saw that coming? I know, it’s counterintuitive when we think of all the challenges PV brings—the pain, the twisted road to diagnosis, and, oh yeah, the fact that no one actually knows what the heck it is. My mother kept calling it lupus for the first two years after I was diagnosed. My mind understood that she was just trying to find a reference point of understanding, but my heart was bruised each time I had to explain it to her.

The surprise is that as your walls crumble, you can discover the rawest part of your strength and how to harness it in magical ways.
I recognize that it is much easier for me to think about the gifts I received from PV two years into remission, but the voice you hear today is over seven years old. My journey began in 2011 at the severe end of this illness with wounds/blisters over 85 percent of my body. On Memorial Day weekend in 2011, I landed in the emergency room in so much pain that I could not stand up straight without assistance. Specialists were called in from their long weekends because my care required it. Months after being discharged from the hospital where I was finally diagnosed, one of my specialists, Dr. S, told me he was afraid when he saw me in the hospital because my skin was gray.

I’m sure this makes the idea of viewing PV as a gift even stranger. However, I maintain that my life is richer and more complete because PV changed it in the best possible way. It forced me to be still, something I had no idea how to do and no desire to learn. Stillness allows you to listen to your mind, soul, and body. It gives you the opportunity to move on those quiet discoveries that come when you listen to your inner voice. Stillness creates a clear channel for God (or your higher power) to speak to you with such power that you have no choice but to move with certainty into your purpose.

PV forced me to learn that real strength comes from vulnerability. When you move from being ferociously independent to depending on friends and family to do the simplest tasks for you, like opening a bottle of Gatorade due to blisters on your hands, you quickly become humble and vulnerable. The surprise is that as your walls crumble, you can discover the rawest part of your strength and how to harness it in magical ways.

PV uncovered the creativity that lay dormant in my spirit. This piece would not be possible without it. I write poetry now. There are moments when words come to my mind with such intensity that it’s as if they are pouring out of my spirit. I’ve learned to use words to breathe life into emotions. The clouds, sunsets, and nature in general are more beautiful to me because I slow down long enough to savor them. PV pushed me to take pictures of these scenes as a I stand awestruck by the beauty that surrounds me each day.

PV reordered my values. I always believed that my family and friends were the most important things in my life. But if I’m being honest, I’d say that my actions indicated that my career was my priority, with those I love coming a very close second. Now I seek quality time with my family and friends often. My goddaughter laughs at me because I always talk about making memories. If I have to choose between work and spending time with those I love, there is no hesitation.

Finally, PV has made me fearless. I feel in some ways like a superhero, which is fitting since my childhood idol was Wonder Woman. I approach life with a peaceful certainty that I can’t be broken, and that difficulties arise to light the pathway for growth. If I can survive PV, I can get through anything, and so can anyone in my village (my friends and family). That’s not optimism, it is clarity based on fact and immovable faith. Everyone’s journey is unique, but I encourage you to consider one thing: Is it possible that even though you didn’t ask for pemphigus or pemphigoid, it ended up enhancing your life in unexpected ways?

Staci White

Staci White is the Operations Manager for Genetics Services and the Institute for Child Development at Hackensack Meridian Health. She currently lives in Hackensack, New Jersey. Staci was diagnosed with pemphigus vulgaris seven years ago and is celebrating two years in remission.
Rare Disease Week on Capitol Hill 2019

Shannon von Felden

Rare Disease Legislative Advocates (RDLA) will bring together over 500 patient advocates in Washington, DC, for a week of events dedicated to empowering patients, families, friends, and healthcare professionals to become legislative advocates. During the week of February 24-28, 2019, advocates will have an opportunity to meet with members of Congress and learn best practices for successful advocacy.

Rare Disease Week on Capitol Hill 2019 kicks off on February 24 with a documentary screening and cocktail reception. On February 25, patient advocates will attend the all-day Legislative Conference to learn about federal legislation and policies that affect the rare disease community. Policy experts from Capitol Hill and nonprofit organizations will share their expertise. In addition, advocacy professionals will teach attendees how to be effective advocates on the Hill and build strong relationships with their members of Congress.

On February 26, a Lobby Day breakfast will be held with keynote speakers. After breakfast, 500 rare disease advocates will go to Capitol Hill to meet with their senators, representatives, and congressional staffers to discuss key legislation, policies, and the Rare Disease Congressional Caucus.

The next day, the Rare Disease Congressional Caucus will host rare disease advocates and congressional staffers for a lunch briefing. Later in the evening, the Rare Artist Reception will feature the 2018 Rare Artist contest-winning artwork and highlight the importance of art as therapy for rare disease patients.

We will close out the week at NIH in Bethesda, Maryland on February 28, when the NIH will host Rare Disease Day at NIH. This event aims to raise awareness about rare diseases, the people they affect, and NIH research collaborations to advance new treatments. The EveryLife Foundation will be there to meet patients and provide information on their programs.

RDLA offers travel stipends to participants to offset the cost of attending Rare Disease Week on Capitol Hill. Stipend awardees in Maryland and Virginia will
receive $400, and awardees in the rest of the continental United States will receive $800. Stipend awardees in Alaska, Hawaii, and Puerto Rico will receive $1,000.

Two stipends will be awarded per state and limited to one per family. Stipends are prioritized to have a diverse representation of rare diseases and for those who have not attended Rare Disease Week or received a stipend in the past. The 2019 travel stipend application is open until December 14, 2018, and can be found at rareadvocates.org/rdw. Applicants will hear by December 21st whether they will receive a travel stipend or have been placed on the waiting list.

Registration for Rare Disease Week on Capitol Hill begins on January 3, 2019. A hotel room block has been organized at the Washington Court Hotel in Washington, DC, between February 24 and 28 for $219 per night. Attendees can contact the Washington Court Hotel directly and make reservations with the “EveryLife Foundation” room block to reserve with this rate.

We are excited for this powerful week of events and to continue to advocate with the rare disease community. Shannon von Felden is a healthcare policy and advocacy professional with experience on Capitol Hill and with national nonprofit organizations. She joined the EveryLife Foundation in 2018 and leads the Rare Disease Legislative Advocates program.

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Information on Rare Disease Week on Capitol Hill 2019, the travel stipend application, and registration for the event can be found at: rareadvocates.org/rdw.

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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
As I write this, I’m sitting in my dermatologist’s office. The doctor I’m about to see is very well-respected in the pemphigus and pemphigoid (P/P) community and has been an amazing advocate and researcher. But this is the first time I’m seeing him in a clinical setting and not at a large dermatology convention. I’m sitting here because I think I’m having a flare.

Many in our community know my story: It took 17 months for me to be diagnosed with pemphigus vulgaris, I spent three years on high-dose prednisone and mycophenolate mofetil, and I’ve been in remission for five glorious years. I’ve shared my journey with thousands of dental students and professionals to ensure that other patients won’t experience similar delays in receiving a correct diagnosis. I’ve spoken to hundreds of dermatologists so they know the impact they can have on our lives. I’ve advocated to state and federal legislators to get them to support bills and initiatives that will help our community. However, I can’t escape the initial feeling of dread after realizing that two lesions in the back of my throat won’t go away.
Still, as I sit and stare at apothecary jars of cotton balls, tongue depressors, and cotton swabs, I realize the strength I have in coming here. It is not easy to admit there is a problem. But after searching for so long, I know the name of my problem and how to treat it. I’ve found wonderful and knowledgeable doctors and nurses familiar with my disease. (This alone brings comfort and relief knowing that they get it, unlike so many of their colleagues.) And now, I’m not waiting for my whole mouth to break down and fall apart, or lesions to begin forming on my skin. I’m taking action and stopping this early.

I’m a fighter and a warrior, like many of you reading this article. I fought my body, my mind, and the medical system that just wanted to brush me aside. I followed dead-end roads. It may be time to do it again, but this time, I’m not doing it alone. I have my healthcare team and the IPPF community. We will work together if this is truly a flare. I’m a survivor. Every day is a new day, and I’m still here. Every day I appreciate that I don’t have to think about how I will put on pants or drink from a straw without tearing skin from my body. I will do this again and again if I need to.

These two lesions are a signal of strength and will show the tenacity inside me. I know it’s just a momentary setback that my doctors and I will fight side by side to bring me back to “normal.” This is only a lesson—a lesson that I stopped listening to what my body needed. I got too busy, too tired, and I didn’t rest or take care of myself when I needed to. A lesson that I need to practice my self-care as well as I tell others to do the same. Just like a boat flare, it’s a light shot into the sky to show where I need to point my attention.

Leaving the office, I’m relieved. My phenomenal doctor assured me that I’m still considered to be having transient lesions. He reassured me that it was good that I came in. While it’s not the best news, it could have been far worse. I’m leaving with a topical prescription that should do the trick. My doctor made sure I was well-informed about how to use the medication and about any follow-up care. This is empowering as a patient. I’m also leaving the visit with the knowledge that I’m in good hands and a feeling that I’m well cared for. I’m lucky to have an expert within driving distance.

No matter what happens on this emotional and physical journey, I know I’m in the right place. As part of the IPPF family, I’m blessed to have access to a list of providers who are knowledgeable about P/P. I’m part of a large community of people who just “get it,” to whom I don’t have to explain the fear of going on high doses of prednisone or the dread and fear of finding a new lesion. My friends with P/P inspire me every day by living successful and productive lives, and I bask in the encouragement that they give me. I know our community will always be there to offer words of wisdom and support whenever I need it.

It may be time to do it again, but this time, I’m not doing it alone.

As you read this article, I hope you know that these same resources are also available to you. If you are feeling alone and isolated, know that there are IPPF Peer Health Coaches you can speak to who “just get it.” Our coaches are patients too. They know what it’s like to have questions and are happy to share the knowledge they’ve learned from their own journey. They are also there to just listen. We all need somebody who understands, who can help us.

RareConnect is another great resource. This discussion forum is not run by the IPPF; however, it connects people from around the world and is a great place for rare disease patients, families, and patient organizations to come together online. It can be very helpful to learn how others manage their diseases.

You can also download recordings of past Patient Education Calls and listen to them at your leisure. These calls feature leading experts in P/P who share their knowledge and answer questions from patients. There are about four years’ worth of calls waiting for you on the IPPF website: www.pemphigus.org

The website also has many other resources, such as local support group information and a “Find a Doctor” map. As always, don’t hesitate to reach out to the IPPF. We are happy to help. We all need somebody to talk to or learn from, and when you are ready, the IPPF will be there. We’re in this fight together—you are not alone!

Becky Strong is a PV patient and the IPPF Outreach Manager. She was diagnosed in 2010 and is currently in remission. She lives in Michigan with her husband Tim and her young family.
I hope this finds everyone in good spirits and with clear skin. I title this “The IPPF Family” because I have been around a lot of people and organizations and truly feel that the IPPF staff is my family. The IPPF educated me on my pemphigus vulgaris (PV) after I was diagnosed in 2012 by a local dermatologist in Nags Head, NC. The dermatologist referred me to Dr. Donna Culton at UNC Dermatology. Without her, I do not think I would be here today. She not only saved my life, but she also led me to the IPPF. I was surprised to learn that a foundation existed for my disease.

I will never forget the day I was introduced to the IPPF. I was working in Cape Hatteras, NC. That morning, the phone rang with a California number. Normally I do not answer unknown phone numbers, but for some reason I decided to answer. And let me tell you, it is the best call I have ever received! Marc Yale, IPPF Executive Director, was on the other end and we talked for about an hour. It was the first time I had spoken with anyone with my disease. He assured me that things were not as bad as they seemed. He talked me off the ledge so to speak.

Marc went on to let me know about several patient education opportunity events and resources available on the IPPF website. Over the following months, I went through two separate rituximab treatments and a clinical trial for a new medication. The trial had little success, but the rituximab really started to help.

While in periodic contact with Marc, he let me know about the IPPF’s upcoming research symposium to take place prior to the larger International Investigative Dermatology meeting in May 2018. He asked me if I was interested in sharing my experience as a patient involved in clinical trials. The hope was to provide a patient’s perspective to the doctors and researchers attending the meeting. I reluctantly agreed.

With the help of the IPPF, we can heal our skin.
(I’m not a crowd person). To my surprise, it was the most eye-opening thing I’ve ever done.

As patients, there are many things we can do to help the IPPF, our doctors, pharmaceutical companies, and others win our fight against these diseases. From participating in clinical trials to volunteering with the IPPF, there is something for everyone.

As of today I feel lucky that I have now been to Orlando, FL, for the IPPF Research Symposium in May 2018; Washington, DC, with the American Academy of Dermatology Association (AADA) and Coalition of Skin Diseases (CSD) to help advocate for pemphigus and pemphigoid in July 2018; and my first Patient Conference in Durham, NC, where I volunteered and spoke briefly on my experience with clinical trials to break down barriers to patient participation.

So please, if you are able to, volunteer with the IPPF. While there are things in life that you can’t do anything about, like having PV or bullous pemphigoid, this is something you can do. It’s possible to help not only yourself, but also others that are in the same boat and might not yet be able to fight. The IPPF makes it easy to volunteer with many different opportunities in various capacities. These opportunities vary from helping out at events, speaking, and fundraising (which is extremely important for a nonprofit organization). Depending on the amount of time you have and what you’re comfortable with, an opportunity exists.

All the events I have attended were fantastic! The one that has impacted me the most, though, would have to be my visit to Washington, DC, to advocate “On The Hill.” We met with senators, congressional members, and their aides. It felt like we were really making a difference. If it weren’t for the IPPF and other patient organizations, I never would have had that opportunity. Please consider being a part of something bigger than any one of us alone. With the help of the IPPF, we can heal our skin.

As for the IPPF, there is one word to describe each and every one of them: caring. I have dealt with each one of them at some point, and they truly care about us. IPPF Executive Director Marc Yale is never too busy to help. Outreach Manager Becky Strong is in the trenches at dental schools and other locations, sharing her experience with P/P with students and dental professionals, as well as with the patients who contact her and Outreach Assistant Amethyst Yale. IPPF Peer Health Coaches have helped so many, and they offer personal tips they’ve learned on their own journey. Nelly Filippov, IPPF Administrative Assistant, is always hard at work coordinating the logistics of all the IPPF does. Patrick Dunn, Communications Manager, and Anna Lane, Communications Assistant, send out each and every email from the IPPF, as well as so many other communications from the foundation. The IPPF is a team of caring people, and it shows in all that they do. As long as I’m able, I will continue to help the IPPF in any way I can.

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Amethyst Yale, Becky Strong, and Jeff Weisgerber

Jeff Weisgerber is from Nags Head, NC, otherwise known as the OBX. There he is the General Manager of Brabble Insulation and loves to spend time with his two children Jackson (15) and Peyton Grace (11), as well as the family mascot: an eight-month-old female Rat Terrier, Inka. He was diagnosed with PV in 2012 and has since been through two trials. He is currently going on his third and fourth infusions of rituximab with impressive results.
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Together, we will HEAL OUR SKIN!

Find out more at pemphigus.org/givingtuesday
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Thank you to all the volunteers who have supported the IPPF’s mission of improving the quality of life for all those affected by pemphigus and pemphigoid. Your dedication provides immeasurable hope to the entire P/P community.

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