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Message from the Executive Director

Dear Reader,

Welcome to our second edition of the Quarterly for 2023. By the time this issue is published, I will (hopefully) be enjoying a few days off with my family on our summer vacation. It has been a busy first half of the year, and I’m looking forward to unplugging in nature for just a little while. At the same time, I am also finding this to be a good chance to reflect on the work we’ve done at the IPPF so far this year, as well as everything we hope to accomplish in the second half of 2023.

As you’ll see on the next page, the IPPF has traveled around the world to represent the pemphigus and pemphigoid community in recent months. In March, we hosted a symposium at the American Association for Dental, Oral, and Craniofacial Research Annual Meeting for dental researchers and professionals in Portland, OR. We then participated in a panel at the American Academy of Dermatology Annual Meeting in New Orleans and hosted a meeting of autoimmune bullous disease experts. In April, the IPPF attended a Coalition of Skin Diseases Hill Day event in Washington, DC, with over 40 advocates and 80 meetings with federal legislators. In May, we hosted a satellite symposium in Japan at the International Societies for Investigative Dermatology that focused on pemphigus and pemphigoid. We also participated in a panel discussion at the World Orphan Drug Congress in Washington, DC. Finally, in June, the IPPF attended the GlobalSkin ELEVATE Conference in Belgium, which focused on strengthening connections across world regions and disease areas.

Throughout this issue, you’ll not only read about the work the IPPF is doing to continue elevating the voice of the patient community, but you’ll also find stories from patients themselves. Whether they are stories of self-empowerment through rare disease advocacy, or hope shining through a long diagnostic and treatment journey, these stories are always the most compelling part of the Quarterly. After all, they’re the reason the IPPF exists, and the inspiration I carry with me wherever I go.

I hope you enjoy this issue as much as I do!

Patrick Dunn, IPPF Executive Director
patrick@pemphigus.org
Events Update

**American Association for Dental, Oral, and Craniofacial Research (AADOCR) Annual Meeting**

On **March 15**, the IPPF hosted a symposium at the American Association for Dental, Oral, and Craniofacial Research (AADOCR) Annual Meeting for dental researchers and professionals. Becky Strong (IPPF), Dr. Carol-Anne Murdoch-Kinch (University of Indiana), Dr. Diana Messadi (UCLA), and Dr. Jennifer Webster-Cyriaque (National Institutes of Health) highlighted pemphigus and pemphigoid (P/P), described the etiology, diagnosis, treatments, and stressed the need for more global research.

**American Academy of Dermatology (AAD) Annual Meeting**

On **March 18**, Becky Strong, Donna Culton, MD, PhD, University of North Carolina at Chapel Hill, Annette Czernik, MD (DermMedical), Brittney Schultz, MD (University of Minnesota), and Heather Holahan, MD (University of California Los Angeles), participated in a panel at the American Academy of Dermatology (AAD) Annual Meeting in New Orleans. Their session, “Pemphigus and Pemphigoid: Evidence-Based Updates,” focused on the symptoms, diagnosis, current treatments, and pipeline research of these diseases and tips and tricks of living with P/P. Also at AAD, the IPPF hosted a meeting of international autoimmune bullous disease experts. During the research-focused meeting, Patrick Dunn and Marc Yale provided updates on the IPPF’s advocacy and research initiatives.

**Coalition of Skin Diseases (CSD) Hill Day**

On **April 25**, Becky Strong attended a Coalition of Skin Diseases (CSD) Hill Day event with over 40 advocates and 80 meetings with federal legislators. Patient advocates asked for support of the Safe Step Act and HELP Copays Act which improve access to treatments for patients, along with robust funding for the NIH/NIAMS dedicated to dermatology research and for the Centers for Disease Control and Prevention’s chronic disease awareness and education program. While on Capitol Hill, the CSD also hosted a briefing highlighting the impact of skin disease, current challenges, and how Congress can help (where Becky was asked to share what it was like living with a rare skin disease).

**International Symposium on Autoimmunity Targeting the Skin: Pemphigus, Pemphigoid, and Beyond**

Patrick Dunn, IPPF Executive Director, attended the International Societies for Investigative Dermatology (ISID) Meeting in Tokyo, Japan from **May 10-13**. The IPPF also co-organized the International Symposium on Autoimmunity Targeting the Skin: Pemphigus, Pemphigoid, and Beyond, which occurred immediately following the ISID from **May 14-15**. The goal of the symposium was to bring clinicians, researchers, and industry partners to share the latest information in the pathogenesis and treatment of pemphigus, pemphigoid, and other autoimmune-related skin diseases. In addition to clinical and scientific data, essential discussions were held on the disease’s pathogenesis, targeted therapeutics strategies, and therapeutic efficacy evaluation.

**World Orphan Drug Congress USA**

Patrick Dunn, IPPF Executive Director, attended the World Orphan Drug Congress USA in Washington, DC, from **May 23-25**. The event brought together leading pharmaceutical and biotech companies, government and regulatory authorities, patient advocacy groups, payers, investors, and solution providers. On **May 24**, Patrick spoke on a panel session with Stephanie Duffy, Global Director of Patient Advocacy and Engagement at the Janssen Pharmaceutical Companies of Johnson & Johnson, about the patient voice and collaboration throughout the clinical development process.

**GlobalSkin ELEVATE 2023 Conference**

Marc Yale, IPPF Research and Advocacy Coordinator, attended ELEVATE 2023 in Brussels, Belgium from June 1-4. The patient organization leaders conference focused on strengthening connections across world regions and disease areas. Attendees had interactive discussions with industry representatives, received updates on the latest issues facing dermatology patients and patient organizations, as well as patient impact data from the GRIDD study.
Join the heart of our community

BECOME A HEALING HERO

Healing Heroes go above and beyond to support our community by making sustaining, monthly gifts to support our mission of improving the quality of life for all those affected by pemphigus and pemphigoid.

pemphigus.org/hero
While dental curriculum may vary slightly between universities, it is paramount that all aspiring dentists take Oral Pathology. During this rigorous course we are educated on hundreds of diseases that not only affect the oral cavity, but that have systemic manifestations as well. In February 2023 I was fortunate to hear Becky Strong, IPPF Outreach Director, speak as a guest lecturer for our Oral Pathology class at Rutgers University School of Dental Medicine, directed by Dr. Yingci Liu and Dr. Richard Bowe. Becky kindly and courageously shared with us her arduous journey to a pemphigus vulgaris (PV) diagnosis.

For the first two years of dental school, our curriculum is heavily didactic as we build and reinforce a strong foundation of knowledge and exercise our hand skills in preclinical simulation labs before beginning to treat patients. In these didactic courses we learn an abundance of knowledge regarding the clinical presentations, etiology, pathology, predilections, diagnosis, treatment, and outcomes of oral and systemic diseases, including pemphigus and pemphigoid (P/P).

In Oral Pathology, we learned that P/P are rare; while I am well-educated on the disease, when I heard that, I personally thought it might not be a disease I would encounter in my future clinical experiences. However, after listening to the daily trials and tribulations that Becky had to endure at the hands of this debilitating disease, the importance of readily identifying even the...
rarest of diseases and conducting the proper definitive diagnostic tests was further highlighted in my mind.

The oral cavity is the mirror of the body, and as dentists we are tasked with more than just cleaning teeth and placing fillings. As observed in patients like Becky, sometimes the first appearance of a more serious, systemic disease can be observed in the oral cavity well before other physical signs and symptoms have manifested. What prompted Becky to begin seeking medical assistance was the appearance of “water blisters” and “canker sores” well in advance of other presentations. As dentists, it is our responsibility to identify these subtle indicators of disease and rule out even the rarest of diseases by taking a thorough medical history of the patient, asking the right questions, and ordering the appropriate diagnostic tests. These critical steps will help us to arrive at the most effective treatment for our patients and hopefully prevent years of pain and suffering.

On the precipice of treating patients in a clinic, this lecture with Becky was particularly beneficial as I have a new perspective and a deep appreciation for the insight that she has so kindly provided. I will always keep Becky’s sentiments in mind when treating all patients. As dentists, while our specialty is diagnosis and treatment of the oral cavity, we must be vigilant not to hyper fixate on the oral cavity and remember to comprehensively listen and observe the patient in front of us as a whole person.

My time spent in the research lab, working in private practice, and in the classroom demonstrated to me the deeply touching impact that case outcomes can have on patients when you have a strong dedication to service, delicate handiwork, and aesthetic sensibility. To me, dentistry embodies both my interdisciplinary interests and passion for helping others.

I am excited to begin treating patients regularly in fall 2023 after studying and practicing diligently for the first two years of school. I am ready to apply the skills I’ve developed to improve the lives of my patients.

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Madison Costello is a second-year dental student at the Rutgers University School of Dental Medicine. In her free time, she enjoys hiking, listening to music, and art history.
Introducing the IPPF to Dermatologists at the AAD Annual Meeting

Donna Culton

The 2023 American Academy of Dermatology (AAD) Annual Meeting was held from March 17-21 in New Orleans, and it did not disappoint! As many of you know, the AAD meeting is one of dermatology’s major meetings typically attracting over 15,000 attendees including physicians, residents, fellows, and industry leaders from the US and internationally. The meeting provides over 300 educational sessions to share updates on clinical findings, diagnosis, and treatments of a wide variety of skin diseases.

Once again, we had the privilege of leading the session—Pemphigus and Pemphigoid: Evidence-Based Updates. Annette Czernik, MD (DermMedical) and Heather Holahan, MD (University of California, Los Angeles) shared updates and challenging cases on pemphigoid, while Brittney Schultz, MD (University of Minnesota) and I discussed updates and challenging cases in pemphigus. However, the star of the show is always Becky Strong (IPPF Outreach Director). Becky shared her story of delayed diagnosis to emphasize the importance of early consideration of these diseases and the need for early biopsy. She also shared tips and tricks for oral and wound care for physicians to pass on to their patients.

This session is aimed at providing updates and practical tips for improved diagnosis and treatment of these rare diseases to physicians across the country, most of whom do not see pemphigus and pemphigoid (P/P) patients very often. Our goal is for these physicians to feel more confident in their ability to recognize and diagnose P/P. I love sharing the different clinical findings of these diseases, the nuances to getting a confirmed diagnosis, and treatment considerations. However, my favorite thing to share is what I consider my secret weapon: the IPPF. Introducing the IPPF to other physicians invites them and their patients into the IPPF community with access to trusted information, patient education webinars, research and advocacy opportunities, peer coaches, and support groups. While individual diagnosis and treatment discussions happen with physicians, discussions of mental health aspects of disease and tips on how to live with P/P on a day-to-day basis often comes from the IPPF community. As you all know, living with these diseases is a long and often difficult journey and having the support of a community who understands is one of the most important aspects of treatment. As a physician, I feel so fortunate to be a part of the IPPF community and am always excited to invite others to join us in support of patients through the IPPF’s mission to improve the quality of life for all people affected by P/P through early diagnosis and support.

Dr. Culton is an Associate Professor of Dermatology at the University of North Carolina (UNC) at Chapel Hill. She serves as the Director of the Clinical Immunofluorescence Laboratory, the Director of Faculty Affairs, and the Associate Director of the Clinical Trials Unit at UNC. She sees pemphigus and pemphigoid patients from North Carolina and neighboring states.
In February 2019, I suffered a pulmonary embolism and shortly thereafter began to have blisters in my mouth. Over the next 18 months lesions appeared over different parts of my body. After many specialists and medications, I was diagnosed with pemphigus vulgaris (PV) in December 2021. I have been treated with all the therapies that are appropriate for PV. Fifteen months later I was feeling well enough to use this experience to help others who share this disease. I first contacted the IPPF to gain more information about PV and advocacy. That’s when I learned about the 2023 Rare Disease Week on Capitol Hill in Washington, DC, from February 28-March 2.

The first day, I attended the National Institutes of Health (NIH) Rare Disease Day. There were a number of sessions by employees of NIH, remarks from the Rare Disease Congressional Caucus and case studies by Rare Disease Legislative Advocates (RDLA). It was clear to me by the end of the day that those of us (and members of our families) who suffer from rare diseases face similar challenges.

The next two days were spent with the EveryLife Foundation for Rare Diseases learning about all the important issues that advocates needed to bring to the attention of our congressional representatives on Capitol Hill. There were several presentations by representatives from the US Food and Drug Administration (FDA), the NIH, and the EveryLife Foundation who provided us with the specific asks. We spent the second day of the conference meeting with our state’s senators, legislators, and staff members asking their offices to take specific actions regarding appropriate pending bills and laws. In addition, we asked that the congressional members join the Rare Disease Congressional Caucus and to sign a congressional letter to the FDA requesting that more attention be given to rare disease therapies. Today only 5% of rare diseases currently have FDA-approved medications.

Here are some additional facts about Rare Disease Week:
- There were approximately 600 attendees.
- Three hundred congressional meetings were scheduled.
- I saw President Biden as he was leaving Capitol Hill! He waved and smiled from his car.
- For the first time since I was diagnosed, I met two people in person who share my disease.

Once I arrived home and took time to reflect, I thought about all of those with rare diseases who could not be there in person. Attending this conference was liberating. I no longer feel alone and am more energized than ever to advocate for those of us who suffer from rare diseases. I am looking forward to future advocacy opportunities.

Betty Tudisco resides in Rochester, NY. She spent a large part of her career in the banking industry and retired in 2013. She spends her time traveling and working as a consultant.
Advocacy in congressional offices is a gradual, sometimes frustrating, process that requires patience and persistence. Meetings are rarely more than 20 minutes long since staffers are always juggling several issues at once. Legislation often gets stuck in committees and may need to be reintroduced over several sessions of Congress before it gets to the Senate or House floor. Budget questions can be a tough sell. Establishing working relationships with legislative aides can take time. When a new Congress has seen, as this one has, substantial turnover, advocates may be dealing with inexperienced representatives or senators, let alone staff members.

What I’ve learned, though, is that without keeping important issues in front of our legislators and letting them know their constituents have a need to be heard, the probability of effecting real change is considerably lower.

Which is why, on March 29-30, I was happy to represent the IPPF in Washington, DC, as part of the 2023 Advocacy Day activities hosted by the American Association for Dental, Oral, and Craniofacial Research (AADOCR), the American Dental Education Association (ADEA), and the Friends of the National Institute of Dental and Craniofacial Research (FNIDCR), NIDCR being an agency within the National Institutes of Health (NIH). That may be a lot of initials to try to keep straight, but the main thing to remember about them is that these three organizations share many of the same legislative concerns and have joined forces to address those concerns with members of the Senate and House of Representatives.

The IPPF is included in this advocacy effort as a FNIDCR participant. It makes sense for the IPPF to align with organizations dedicated to dental research and education, since dental professionals are often the first medically trained people to see the oral lesions that are common initial symptoms of pemphigus vulgaris (PV).

A virtual training session the week before the event introduced us to the “asks.” Asks are the legislation and appropriations bills we would be encouraging members of Congress and senators to support. This meeting also presented guidelines on how to conduct more effective meetings. When we got to Washington, DC, a group of about 70 advocates met at the American Dental Association offices for a legislative briefing as well as to get our assignments for the next day’s meetings, meet with our teams of advocates, and receive leave-behind documents for the following day’s meetings.

Advocating on the Hill: A Personal Account

Fred Wish

Advocacy in congressional offices is a gradual, sometimes frustrating, process that requires patience and persistence. Meetings are rarely more than 20 minutes long since staffers are always juggling several issues at once. Legislation often gets stuck in committees and may need to be reintroduced over several sessions of Congress before it gets to the Senate or House floor. Budget questions can be a tough sell. Establishing working relationships with legislative aides can take time. When a new Congress has seen, as this one has, substantial turnover, advocates may be dealing with inexperienced representatives or senators, let alone staff members.

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The next morning, I met with my team to prepare a game plan for each of our meetings: who would speak first, who would cover each of the specific asks, and how to punch up our presentation. Over the next few hours, we met with staff members from the offices of Representatives Jeff Van Drew of New Jersey and Rosa DeLauro of Connecticut, and New Jersey Senator Cory Booker. Our discussions centered around three main points: deferring interest payments for dental students, assuring appropriate funding for NIH and NIDCR, and promoting measures to increase the presence of dental professionals in historically underserved areas.

It was a great help that the team members who accompanied me to Capitol Hill, both students in dental programs, were able to fill in more technical information and relate their own stories from an academic and professional viewpoint. I have a fair amount of advocacy experience, but not being a dental professional myself, I was a little unsure of how I could contribute to alerting and educating federal legislators on these issues. In the end, I believe my perspective as a patient was useful. My story, especially how long it took to get to a diagnosis, and that it was a dentist and then an oral surgeon who first recognized and confirmed my PV—after having been told by a dermatologist that my condition was not PV—helped to personalize the need for action.

The IPPF has been particularly effective in partnering with organizations that share its legislative vision and in recruiting patient and caregiver advocates to join in the effort to improve diagnosis and treatment, and to push the boundaries of research for the benefit of those experiencing pemphigus and pemphigoid. So when Marc Yale, IPPF Advocacy and Research Coordinator, asked whether I would travel to Washington, DC for the second time this year, I did not hesitate to say yes.

Fred Wish is a PV patient who lives at the Jersey Shore. Legislative advocacy in one form or another has been part of his life since 1992. He retired from full-time work in 2010 and owns a writing and editorial service company with his wife, Loretta. He also enjoys working with the local homeless community, being a member of a classic rock band and spoiling his grandson at every opportunity.
Thank You

to the Sy Syms Foundation and the Unger Family Foundation for their continued support of the IPPF Awareness Program
I am lucky to have made it through pemphigus vulgaris (PV). I wish I had received an accurate diagnosis for PV sooner than I did, though. The specialists who ended up treating me at a leading research hospital explained, “You cannot blame a general practitioner for not recognizing this disease, because most of them have never seen it, and they never will, either.”

It was well over six months of bewilderment—mine and that of my primary care physician—about an array of sores, gruesome and glorious, before anyone mentioned to me what PV was or that I had it. The earlier erroneous opinions spanned a range of symptoms. I had blisters. I had a rash. I had various skin issues as a child. So this initially appeared to be another version of a familiar problem. But the deterioration was ceaseless.

My own guess was bedbug bites. I had taken a trip to New York City. I had read the place was infested with bedbugs, and even luxury hotels were not free of the problem. The doctor’s assessment was spider bites. She said an arachnid had inflicted a series of punctures. That would have been a determined enemy. A dermatologist said contact dermatitis or eczema. He said I had been exposed to some substance that was disagreeable. He recommended changing soaps and shampoos.

The truth is the symptoms started off minor. I had a lesion on my back. It alternated between itching a bit and hurting a bit. Then I had something else which looked to be unrelated. I had a blemish on my cheek which would not heal. It was hardly more than a shaving cut. A few patches bothered me here and there. I switched to mild soaps and I always had a sparing touch with laundry detergent.
Over time, I had more spots. That is the right word. Even as a profusion, they were merely spots. Adolescent acne was worse.

One morning, I became alarmed. I woke up and my nostrils were clogged. They had massive booger scabs filling up all the available space. Then I had another symptom. My mouth had ulcerations that would form, fill with blood, and erupt; releasing a salty taste.

I went to the dermatologist again. I mentioned I also had a white stye, a hard swelling, under my tongue. The technical term for that location is the lingual frenulum, the central stretch between the bottom of your mouth and your tongue. The more junior partner in the medical practice ordered a biopsy. The more senior colleague called me from vacation in Latin America.

He said he had suspected it: I had PV. They confirmed it with the lab results. Its advancement accelerated.

Soon, I had lesions spreading all over my chest and my back. They flowered at night. They opened up and blood poured out. We had to put down towels over the sheets to protect the bed. My t-shirts needed to be bleached every day, and then we just threw them out because they were too stained.

Eventually, these stigmata covered my torso, extending to a smattering on my legs, encircling my privates. The deepest were divots.

I would stare at myself, a stranger, in the mirror. My mortality was manifest. It was fascinating as only what is disgusting can be.

I was put on methotrexate and prednisone. Although the doses were increased again and again, the malady remained more powerful than the medication. The side effects were a doozy nonetheless. The pills made me simultaneously lethargic and paranoid, able to sit in my basement wondering if I would ever emerge and not useful for much else.

As an avid runner prior to my PV diagnosis, I can measure my status with PV through my running. Before PV, I was considered in “excellent health.” That likely was due to having taken up running. During PV, I could not run, and, for that matter, I was supposed to stay out of the sun altogether due to the medications I was on. After PV, I was back to racing, albeit at a slower pace.

About a year and a half after I was diagnosed, and after a successful course of rituximab, I felt confident enough to sign up for another half marathon. The time off, not to mention the ailment itself, had taken a toll on my performance. Prior to PV, I had a personal record of 2:17. Coming back, I was satisfied to break 3:00. Every minute difference is substantial if you know the sport. My pace had decreased from a sub-11-minute mile to well over a 13-minute mile. Elite marathoners are literally twice my speed.

I had persevered though.

Five years later, I have had my strongest season. Traveling around the nation, after the COVID-19 pandemic, I managed 38 half marathons, one full marathon, and seven other races including two at high altitudes (starting in Silverton, Colorado, at 9,318 feet above sea level). I am still slow. I am improving. My new best is 2:27. I have enough endurance to run two half marathons in a weekend and, once, even two in a single day.

I intend to run as long as I am alive. I am convinced that running has been crucial to making it through PV.

Frank Wu is the President of Queens College, The City University of New York (CUNY). He is a published author, an avid runner, and theatregoer.
Sharing our story is an amazing way to bring to life diseases like pemphigus and pemphigoid (P/P). Through sharing who we are and how the disease has affected our lives, we bring humanness to an otherwise objective list of symptoms. We are more than blisters, lab results, and biopsy specimens. We are wives, mothers, fathers, brothers, friends, uncles, aunts, neighbors, professionals, pet parents, and many more to people in our lives and communities. We’ve had our worlds turned upside down by a rare disease, and it’s important to feel ready when we share our stories.

At the beginning of our diagnoses, we often consume all the information we can about P/P and crave to learn how others not only survive, but thrive with a rare diagnosis while taking medications with potentially life-threatening side effects. We might be hungry to learn more about how we can minimize side effects and to get into remission, as well as how to care for our skin, mouth, mucous membranes, and lesions. We read about what the research is telling us about disease, treatments, and one day a cure. And we read about other patients’ journeys so we know if we are normal-looking.

We search, we scroll through pages and pages on the internet, and we read peer-reviewed articles (many times having to google the terms and medicalese used) to gain an understanding of what is happening to us. And we laugh and cry reading the stories of others as we ourselves go down rabbit holes looking for answers. Sometimes, even the most hopeful stories of success are filled with heartache, failure, and pain.

While doing this extensive research, we may realize that our journeys and stories are traumatic. According to the International Society for Traumatic Stress Studies (ISTSS), “medical trauma is defined as a set of psychological [emotional] and physiological [physical] responses to pain, injury, serious illness, medical procedures, and frightening treatment experiences (https://istss.org/public-resources/friday-fast-facts/fast-facts-medical-trauma).

There are many different experiences related to the diagnosis of P/P and subsequent medical treatment that are difficult, uncomfortable, or frightening. From seeing our bodies literally fall apart before our eyes, experiencing pain, and fearing when it’s time to eat or talk with mouth lesions, to the endless blood tests, medical procedures, and doctors’ appointments to try to figure out what is happening to us—it can be too much. It’s important to know that you are not alone.
When I was diagnosed, sharing my story with my friends and coworkers, let alone medical and dental professionals, wasn’t even on my radar. After searching for a diagnosis for about 17 months and going to multiple doctors’ appointments with a large number of different specialists, I was exhausted. Many of the medical professionals I went to weren’t looking at the whole picture; instead they were focused on their own area of specialty. I had amazing things said to me like, “Ewwww, that’s gross,” and, “I can give you medicine and it will make it go away in two weeks, or if we do nothing it will go away in 14 days.” I felt both belittled and dismissed at times. There were times that I told myself things weren’t that bad and asked myself why I was being so dramatic.

For those of us lucky enough to have a diagnosis, we are provided with answers to the many questions in our head. We know that we aren’t making up what is happening to our body. And while a diagnosis points to correct treatments to start to heal our bodies, many times it doesn’t heal our minds or the trauma that we have been through.

While our doctors are working feverishly to fix our physical health, many times patients like us are left to cope with our mental health on our own. And our mental health is just as important as our physical health when dealing with a rare disease. During this time, I encourage you not to be afraid to talk about mental health with your doctors.

If you are considering therapy for your mental health and wellbeing, finding the right therapist is important. Here are some tips and tricks:

- If you have insurance, a great starting place is to connect with your insurance company to find which in-network providers are located near you. You can also explore your benefits to find out about your coverage for therapy and mental health benefits.
- Consult with someone you trust such as a friend, doctor, or colleague about finding a therapist. They might have a therapist they really can talk to and helps them. Hearing about their experience can provide insight into what appointments may be like for you.
- There are several mental health organizations that have trusted databases of licensed providers that you can easily search to find who is in your area.

While a diagnosis points to correct treatments to start to heal our bodies, many times it doesn’t heal our minds or the trauma that we have been through.

The American Psychological Association (https://locator.apa.org/) and the American Association of Marriage and Family Therapists (https://www.aamft.org/Directories/Find_a_Therapist.aspx) are helpful tools. If you are part of a particular community, you may also find resources or local support groups that will meet your needs too.

- Online therapy apps might be helpful as well. Talkspace, Amwell, and BetterHelp offer resources to help you find the right type of therapy and therapist for you. Many people find that using digital or virtual therapy is more convenient to their lives as they do not have to travel. There is also the added benefit of being comfortable in your own environment by attending virtual appointments.

It’s also important to explore the different types of therapy, including cognitive behavioral therapy (CBT), psychodynamic therapy, interpersonal therapy, art therapy, and music therapy.

Most importantly, if you meet a therapist and know they aren’t a good fit for you, speak up and don’t quit searching for the right therapist. It can take some time to find somebody who you feel comfortable with, and who you can trust.

You are not alone and your mental health is an important part of the healing process—as much as healing from our physical lesions. When you are ready, the IPPF encourages you to share your story with the P/P community. We can all learn from one another.

Becky Strong is the IPPF Outreach Director. She was diagnosed with PV in 2010 and is currently in remission. She lives in Michigan with her family.
My story begins when I initially saw an odd skin breakout on my chest in June 2011. Finally, in the fall of 2011, after breaking out with mild boil-type bullous lesions, I went to a dermatologist in Dunedin, Florida, and was given some creams to apply. One week later, after more lesions had appeared, I went back to the doctor and was sent home with a different cream to use. During the next two weeks, the skin started sloughing off my back, shoulders, head, and chest; and lesions or blisters were now below the waist on my thighs, hands, and feet.

During my third visit, the doctor showed me a medical book she was studying for the diagnosis but was unsure of what I had. She took a biopsy and we waited two weeks for the results. Meanwhile, the bottom of my hands, feet, and skin became bullous and were sloughing off at a rapid rate. I had to sleep on black garbage bags to keep the skin and blood from ruining the bedding. The results came back detecting pemphigus foliaceus (PF) and pemphigus vulgaris (PV). At our final visit with that dermatologist, she gave me a printout of the diseases from the medical book and prescribed CellCept®. Well, anyone that has taken CellCept® knows that it takes time for it to work in one’s system.

At the time, my daughter was studying to be a physician’s assistant. She came for a visit, took one look at me, and rushed me over to an immunologist at the University of South Florida (USF) in Tampa. He was kind enough to look at me immediately. I filled out the required forms, met the doctor, and opened my shirt for the doctor to
inspect. He took one look, kept his demeanor, and told me to go directly to Tampa General Hospital and by the time I would get there, admitting orders would be ready.

In the emergency area the doctors looked at me, but unaware of my PF and PV diagnoses they sent me to the burn unit and started me on IVs. The next day, a doctor on staff recommended I be debrided of all the crusting and sores on my skin. I was given a large dose of pain medicine, taken to a large bath-type room and scrubbed and cleaned. I must say that no amount of pain medicine could dull the pain of that experience!

I was taken back to my room and dressed in creams, gauze, and a burn jacket. Yet, my diagnosis was still unknown. A day later and in a lot of pain, I was visited by a mature, confident man, Dr. George Cohen. He was more concerned about what I had versus the pain I was in. He looked at me and said, “I know what you have, and I’m going to fix you up.” Until the day I die, I will never forget that statement and the impact it had on me. Wow! This doctor knew what diseases I had and was going to fix me up. A great weight was lifted at that moment. As the days unfolded and he gave me the details of the disease, treatment, and outcome, I realized it would be a long journey but there was still hope for a good outcome.

After six days of prednisone and intravenous immunoglobulin (IVIg), Dr. Cohen said it was time for me to go home and heal. I was shocked. He clarified that a hospital was unsafe for me due to potential infection with as much open skin as I had.

So off we went. My fiancée picked me up in a Mini Cooper, and we went jostling down the road to go home. Every bump in the road was a nightmare.

Once I was home, I slept standing up because the sores and open skin were everywhere, and if I sat or laid down and then got up, my skin was stuck there and was ripped open once again.

Quickly, my fiancée and I developed garments I could wear: t-shirts with cutoff sleeves split from the center with two looped-through ties for closure and a sarong bottom. Thank goodness for discarding the burn vest. For months, every morning, I showered with Dilaudid, and my sores were dressed with Xeroform. Of note, a week after I was home, my fiancée had to go out of town. I didn’t want to take a shower on my own, but I knew that God only helps those who help themselves, and so I did, screaming all the while.

I am a fighter and a survivor and, fortunately, have a high pain tolerance. I knew that if I did not help myself, it would be harder and longer to heal. I also ate food when I wasn’t hungry and did a lot of meditation and affirmative visualization.

I have many strong beliefs, one being “you gotta wanna,” meaning a person must really want to be better and heal to be their best self. My second strong belief is in my maker. Even if you are physically alone, you are never alone. Higher power is always there for you to tap into for the strength you need when you need it the most.

I understand that everyone handles these horrible conditions differently, and each individual experiences different symptoms and discomfort. With pemphigus and pemphigoid (P/P), one has to endure and try and plow through as best as one can. We engineered using wax paper to sit on so I could sit. I lived in a Lazy Boy recliner for at least six months, not even getting up at night. In time, my condition stabilized, and my skin slowly started to replace itself. When I first got to go outside, even a slight breeze was painful. I was still glad to be outside, even slowly creeping half a block at a time. I was never apprehensive about how I looked or what people might say. I never once ever took my eye off the goal of a full recovery.

CONTINUED
Twelve months after I was diagnosed, I was in good condition—fat from prednisone and with brand new, sensitive baby skin. Since my diagnosis, I have been receiving IVIg infusions and rituximab, which was very hard to get back in 2012. I had a fantastic support group. My fiancée (I call her Saint Toni) dressed my wounds daily for a long time, and told me a thousand times, “You’re going to be alright.” I also had help from my daughter and stepdaughter with doctor visits, infusions, or dressing changes. The patients at the oncology infusion centers were the most uplifting people I met. I really enjoyed their great spirits.

I healed and life was really good. It left me with a wonderful perspective on life, but I knew my journey would be challenging going forward. My lovely wife and I were married in 2012. We celebrated with a big party in our front yard with friends and relatives, but I was experiencing flares even with the CellCept®. The disease rapidly escalated before the wedding, as bad as the first time, and I was hiding sores and taking Codeine for pain. The day after our wedding, for our honeymoon, I went straight to Tampa General Hospital for a week of infusions. During this second bout, I visited an eye doctor because the sores encroached on my eye area. The sores were back with a vengeance. I pushed through to another recovery and became an expert on my condition, such as how to care for my wounds, sores, topical creams, salves, and dressings (Triamcinolone, Vaseline, Xeroform, etc.).

Nine months after we got married, again I was healed, and life was good. I took CellCept® for many years, weaned off prednisone, and started a fitness program. During my big flares, my desmoglein 3 (vulgaris) count was 226, and my desmoglein 1 (foliaceus) was 134. I know that for dermatological medical practitioners, these numbers are not considered high. However, I know my body, and when my numbers get high, I know I will flare soon.

From 2011-2013 and into 2014, P/P consumed my life. I corresponded with Marc Yale, IPPF Research and Advocacy Coordinator, in 2011 and 2012 and always kept aware of what the IPPF was doing. I went to all the patient education conferences and even learned some of the chemistry of the disease. To become your own advocate, it’s important to know everything possible about the disease and to try and understand what is going on with the big picture. Never before has there been as much information globally available as there is now. Support for P/P patients has never been greater; just reach out, and it is there. I cannot say enough about the IPPF and how they have grown, and what they currently are doing and providing. Dentistry and orthodontics awareness alone has saved many people months of non-diagnosis.

In 2018-2019, I experienced a nasty flare deep in my throat—esophageal pemphigus vulgaris. It took 14 tissue samples and five months to get a correct diagnosis. Ouch! That hurt.

My current treatment consists of rituximab infusions every 24 months, clean food, lots of fitness, a lust for life, and a love for everyone around me. Seriously, it’s great to be alive!

Even with what we know today, misdiagnosis still happens and delays our recoveries. I cannot stress enough that you must be aggressive with questioning everything about your condition, research everything that is happening to you, and consult with your doctors. I may not love my condition, yet I have learned to live a very full life with it. I am in tune with my body. I respect, enjoy, and love my doctors. In addition, I enjoy and appreciate everything that the IPPF and the medical professionals are doing to improve the lives of P/P patients.

Please live life as fully as possible and embrace your condition. You might be surprised and have a very long remission. Thank you for taking the time to read my story. As we each have a unique body and chemistry, our experiences will be different.

Marc Friedman is in remission and is living life to the fullest in Clearwater Beach, Florida with his wife and two cats.
IN LOVING MEMORY

Rudy Soto

The IPPF family is sad to share that Rudy Soto, beloved Austin Support Group leader, Peer Coach, and friend passed away on April 14, 2023. Rudy's dedication to the IPPF community has long been an inspiration for all of us at the IPPF. He will be greatly missed.
I n 1983 I was diagnosed with pemphigus vulgaris (PV). What! I was 37 years old and had no idea what it meant or how it might affect my life. I was hardly ever sick as an adult. I had plans and unfortunately with this diagnosis, all my plans changed. I was raising a 6-year-old by myself, but I had a lot of great family support.

My scalp was covered with blisters. I remember the only thing that didn’t hurt was standing naked in the middle of my room. I cried every time I’d step into the shower because the water hitting my head was so painful. I couldn’t get a professional to cut my hair because it was long, but I couldn’t stand having a lot of hair pulling on my scalp. My mom ended up asking a friend to cut it.

I didn’t know what I was going to do with this diagnosis. At the time I was diagnosed, my doctor, who was in fact a wonderful dermatologist, knew what PV was but wasn’t really familiar with how to treat it. So, I was sent to see a doctor in San Francisco (I was in Berkeley). He knew immediately what PV was and put me on 40 mg of prednisone. I didn’t want to stay with the doctor who diagnosed me because he wasn’t very helpful, so I went back to my doctor in Berkeley, Dr. Clarke. I had no health insurance, and after a few months and a bankruptcy,
I was able to get Medi-Cal (California Medicaid). But unfortunately, most doctors wouldn’t take Medi-Cal or Medicare at the time. The doctors who would were rude, and when I said I wanted to be involved with my treatment told me I had to do what they said. So, I went back to Dr. Clarke. She agreed to help me and gave me an amazing discount so I could afford it. She was amazing.

Dr. Clarke helped me manage taking prednisone, which was almost the only drug available to treat PV at the time. Methotrexate was an option, but I couldn’t take it, so I stayed on 40 mg of prednisone for two months. It cleared up my blisters right away. Dr. Clarke suggested we start reducing the prednisone dosage because I was clear of blisters, so I did. At 30 mg I was still clear from blisters, but the moment I went down just 2 mg to 28 mg (most doctors were recommending going down 5 mg at a time, but I didn’t want that), I broke out worse than the first time. My face was covered with sores and a lady at the store asked me, “Who beat you up?” But I was one of the lucky ones. Forty mg of prednisone cleared up my blisters and I went down to 30 mg and stayed there for three years.

I gained a lot of weight. I was fired from my job. It wasn’t great. I started looking for other jobs but there was no internet. I thought about starting a foundation just to find others and feel less alone. I couldn’t find anyone to help me. Besides, I really wasn’t ready. I had to get used to living with prednisone and PV. After three years, I went off prednisone and thought that my PV was in remission. I found a job and a few years later, my symptoms of PV came back with just a few mouth sores but this time I knew what it was. I went right back on prednisone for several months and went into remission.

I still couldn’t find anyone else to talk to about living with PV. My brother and sister-in-law worked in the libraries, so they found an article for me to read. I read a lot about PV and became quite familiar with the disease even though I was in remission. I knew my symptoms were going to come back and, of course, they did when I was taking a trip with my daughter down the coast of California to look at colleges. I decided to wait until I got back from the trip to start prednisone again because I knew it probably wasn’t a great idea for me to drive down that winding, coastal road on prednisone.

I got back from my wonderful trip with my daughter and started prednisone again. Thirty mg was enough to keep my blisters clear, but I couldn’t stay on such a high dosage any more for so long. By then azothiaprine became available so I was put on that medication, and I was able to reduce my prednisone dosage to 10 mg a day. I had to stay on this combination for many years.

I decided after that trip that I was going to start a foundation. But I knew I needed a doctor’s support. From the articles I had read, I found the names of several of the leading dermatologists working on pemphigus and pemphigoid (P/P). I decided to write to them. I didn’t think any of them would respond to just Janet Segall, so I signed my name Janet Segall, PhD. I received a letter back from Dr. John Stanley, Head of Dermatology at the University of Pennsylvania in Philadelphia, who said he couldn’t help me because he was too busy, but that Dr. Grant Anhalt from Johns Hopkins University might be interested. So, I contacted Dr. Anhalt. We met in San Francisco, and with his support the Pemphigus Vulgaris Foundation became a reality.

As the internet evolved, I was amazed at how many people needed help understanding the disease—first PV, then PF, then pemphigoid. We went international and that is where we are now.

Some of you may already know my story and know me. I want to share it again in my first column so that you will have some context. I’m looking forward to writing about the different aspects of P/P and what it means to me. Thank you!

Janet Segall is the Founder of the IPPF and a PV patient since 1983. She is an IPPF Peer Coach and the leader of the Northern California Support Group.
Spotlight

Four Questions with Dr. Animesh Sinha

Our Spotlight section features a medical professional whose work regularly impacts the lives of pemphigus and pemphigoid (P/P) patients. Get to know a new physician, researcher, or other medical professional who knows these diseases best. This issue, we’re featuring Dr. Animesh Sinha.

Dr. Sinha is a Professor in the Department of Dermatology, University at Buffalo, in Buffalo, NY. Following the completion of his MD degree in 1982 from the University of Alberta, Dr. Sinha received his PhD degree in Medical Sciences (Immunology) in 1986 from the same institution. Subsequently, he pursued postdoctoral research at Stanford University in the Department of Microbiology and Immunology. Dr. Sinha’s subspecialty training in dermatology was completed at Yale University/Yale New Haven Hospital. Prior to his appointment in 2011 as Chair of the Department of Dermatology at SUNY Buffalo/Roswell Park Cancer Institute, Dr. Sinha held faculty appointments at the Department of Dermatology, Weill Medical College of Cornell University and at Michigan State University, where he was the Chief of the Division of Dermatology and Cutaneous Sciences. Dr. Sinha is a board-certified dermatologist whose professional goals are aimed at bridging the bench to the bedside. His research is focused on understanding the genetic and immunologic basis of complex skin disorders. He has published extensively, over 150 peer-reviewed articles, including four in the journal Science, and received numerous honors and awards for his academic activities. He is highly sought after as an invited speaker worldwide on a broad range of clinical and research topics.

How did you become interested in P/P?

I became fascinated by the workings of the immune system as a medical student, and I pursued a PhD degree in immunology after completing my MD. I have continued to be involved in basic, translational, and clinical research probing the central conundrum of the immune system, such as how does our body differentiate our own tissues from foreign pathogens and—under healthy conditions—only attack the latter? Of course, when self/nonself discrimination fails, autoimmunity can ensue. Every organ in the body can be affected by autoimmune disease, and since my clinical subspecialization is in the field of dermatology, my research has focused on autoimmune bullous disorders of the skin, particularly the group of diseases classified as autoimmune bullous disorders such as pemphigus vulgaris (PV) and bullous pemphigoid (BP). Specifically, I became interested in which genes predispose individuals to developing autoimmune diseases such as PV. Many years ago, while at Stanford University, I sequenced the key variants of Human Leukocyte Antigen (HLA) genes, known to be master regulators of the immune system, that are overrepresented in PV patients. This allowed us to begin to draw a roadmap from genetics to tissue destruction, and remains an active area of investigation for our lab and others.

What is one thing you’d want all patients to know early on in their journey with P/P?

I would like to emphasize to P/P patients, especially new onset individuals, that while there are many unknowns to disease pathogenesis, the scientific community has made and continues to make significant advances in our understanding of disease mechanisms and strategies for intervention. We have many more options for treatment than we did only a few years ago. So, my message ultimately is one of hope.

What can patients do to better advocate for themselves?

I would encourage all patients to seek out expert care for their condition as soon as possible. Finding the right healthcare professionals with appropriate experience in treating P/P is paramount. Connecting with the IPPF is perhaps the best way to find the healthcare professionals that can help most. Moreover, the IPPF offers an array of resources and a plethora of support services to help patients understand and navigate living (as well as possible) with their disease. Finally, please remember that it is important to advocate for awareness and funding for rare diseases at the local, state, and federal government levels.

What is one fun fact about yourself?

Growing up in Canada, I am an avid ice hockey fan. I unabashedly cheer for my beloved Edmonton Oilers!
As a pemphigus and pemphigoid (P/P) patient, you are invited to participate in ground-breaking research that is being conducted by the International Alliance for Dermatology Patient Organizations (also known as GlobalSkin) in collaboration with researchers at Cardiff University (UK) and University Medical Centre Hamburg-Eppendorf (Germany).

The Global Research on the Impact of Dermatological Diseases (GRIDD) project aims to collect global data on the impact of dermatological conditions on patients’ lives. To collect this impact data, we have developed the new Patient-Reported Impact of Dermatological Diseases (PRIDD) measure, a scientifically sound questionnaire capable of measuring the impact of conditions of the skin, hair, nails, and mucosa from the patient’s perspective. As a Member of GlobalSkin, the IPPF is supportive of this important project.

You are the expert and your opinion matters!

By participating, you will be helping to show clinicians, researchers, and policymakers the true impact of living with your dermatological condition. The data collected will help to inform areas of need for improved care, better treatment options, and more affordable medicine for dermatology patients globally.

GlobalSkin is looking for 10,000 people like you to take part in the study by completing a 10–20-minute online survey. We may also ask you to complete a shorter version of the survey six weeks after you complete the first one to assist in scientifically validating the new measure.

To participate in this important research please follow this link:
https://globalskin.org/GRIDDStudy

The online survey is open from June 5 to September 28, 2023. Please feel free to share the survey link with anyone who you think may be interested. This research has received the required ethical approval from Cardiff University. For more information about GRIDD or GlobalSkin please visit https://globalskin.org/research
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