

2023 YEAR IN REVIEW | NEW BOARD PRESIDENT | VOICE OF THE PATIENT REPORT

Quarterly

Journal of the International Pemphigus & Pemphigoid Foundation

QUARTER 1: 2024

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Quarterly

The Journal of International Pemphigus & Pemphigoid Foundation

ISSUE #114 | Q1 2024

The IPPF is a US 501(c)(3) nonprofit organization. EIN: 94-3207871

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Printed in the USA by our friends at **SUNDANCE PRESS**, Tucson, AZ.
www.sundancepress.com

Message from the Executive Director



Dear Reader,

Welcome to our first issue of the *Quarterly* for 2024. All of us at the IPPF have been busy planning our year, and what a year it will be!

First, 2024 is a landmark anniversary for the IPPF—our 30th! In 1994, Janet Segall had the tenacity and foresight to start a nonprofit organization with the goal of connecting patients who had received the diagnosis of a lonely disease with a funny name: pemphigus. Janet brought together patients and expert doctors, and from there, we grew to become the International Pemphigus & Pemphigoid Foundation you know today. You can read more about Janet's perspective in this issue's "Founder's Corner."

As we celebrate this anniversary, I'm sure we'll find plenty of opportunities to share the IPPF's impressive list of accomplishments from the past three decades. However, as I think about the almost 10 years of my own work with the IPPF, my mind turns to the humanity of this organization. It's the people who have made the IPPF a living, breathing source of hope for so many. Of course, I'm talking about the staff, all of whom have dedicated a chunk of their professional lives to our mission. But it's more than that. It's the patients and caregivers who connect with us for help. It's the people in remission who keep in touch and "pay it forward." It's the researchers and doctors who educate patients while passionately fighting for the best outcomes for all those affected by pemphigus and pemphigoid. It's the volunteers who share a passion for making sure others feel less alone. It's our industry partners who focus on building long-term relationships with this community. It's all of these people who make us the IPPF and form a web of relationships that can all be traced back to the single thread of Janet Segall's desire to help others.

With this in mind, I'm excited to announce that this is also the year that the IPPF returns to an in-person Patient Education Conference! Our first in-person patient conference since the pre-Covid days will be held in Newport Beach, CA, on October 26-27. Indeed, this has been a long time coming. On behalf of the entire IPPF staff and board, we can't wait to see you!

Patrick Dunn, IPPF Executive Director
patrick@pemphigus.org



Meet Our New Board President: Staci White



On behalf of the IPPF Board of Directors and staff, we are excited to announce that Staci White has been appointed as our new President of the Board of Directors. Staci has served as an IPPF Board member since 2020. She has also been active in the IPPF community for many years.

Staci's motto is "fearless joy." She views life's challenges as avenues for clarity and creativity. In 2011, she was diagnosed with pemphigus vulgaris (PV) after being taken to the emergency room (ER) on Memorial Day weekend with wounds/blisters over 85% of her body. Her PV symptoms, though unrecognized as such by any physician who examined her before arriving in the ER, began in the winter of 2010. Staci celebrated seven years in remission on July 20, 2023. It was a hard-fought, five-year journey to remission. She was grounded in faith and surrounded by love each step of the way.

Staci believes that PV changed her life in unexpected but beautiful ways. She is an intuitive, mindful, and

strategic leader with 29 years of experience with non-profit, healthcare, and education organizations. She holds a BA in Psychology and a Master's in Public Administration from Rutgers University, along with a certificate in Diversity and Inclusion from Cornell University, a Lean Six Sigma Green Belt from Purdue University, and she is a Certified Professional Life Coach. Staci currently works for the healthcare network where she was diagnosed with PV as the Director of Student Affairs and Wellbeing at Hackensack Meridian School of Medicine. She is also an adjunct professor at Bergen Community College in New Jersey.

In 2023, Staci became the founder and Chief Coaching Officer for Kitt White Coaching, which specializes in transformational and leadership coaching. Anchored in community service, Staci is a member of Delta Sigma Theta Sorority, Inc., the co-chair for Hackensack Meridian Health's Women in Leadership Team Member Resource, and a mentor.

2024 IPPF International Scientific Meeting

August 29-31, 2024

Under the chosen theme “Pemphix, Πέμφιξ” from the Greek routes to the modern era of developments in clinical recognition, diagnostics, and therapeutics, researchers will come together to share knowledge, exchange insights, and forge collaborative solutions. This meeting offers a unique platform to connect with peers, researchers, and healthcare professionals dedicated to advancing our cause.

The scientific program of the Symposium is designed to include lectures from world-known experts, oral and poster presentations, and thematic round table discussions. We believe that this structure will facilitate and enhance the knowledge and clinical skills of the participants and aim to provide better care to patients globally.

SAVE the DATE



MEETING OF THE INTERNATIONAL PEMPHIGUS & PEMPHIGOID FOUNDATION

Hotel
Makedonia
Palace

THESSALONIKI Greece

2024

August 29th - 31st

www.ippf2024-skg.gr

ORGANISED BY



Professional Congress Organizer





Year in Review: 2023

Patient Education Webinars



3,076

total registrants

11

webinars

Support Groups



478

participants

23

meetings

Patient Education Conference



445

registrants from

27

countries

100

congressional members reached via IPPF advocacy efforts

The *Voice of the Patient Report* was published after the IPPF Externally-Led Patient-Focused Drug Development meeting on January 25, 2023. The report will be sent to the FDA and will provide a reference point for their decisions concerning the approval of potential medicines for P/P.

462

meeting registrants

441

online survey respondents

View the *Voice of the Patient Report* on our website:



Students Reached at Patient Educator Presentations



86

Optometry



220

Medical



1,034

Dental

700

people living with pemphigus and pemphigoid were helped through one-on-one interactions with IPPF Peer Coaches

Scientific Seminar Series

529

total registrants

6

webinars

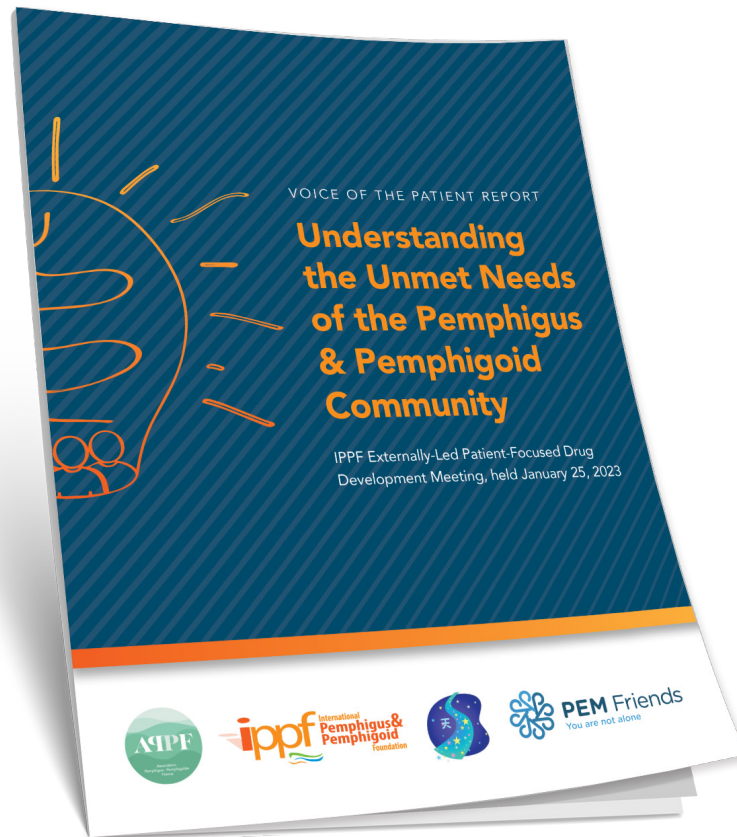
Natural History Study

33

new participants

604

total registrants



To celebrate **Rare Disease Day 2024**, the IPPF announced the publication of *Understanding the Unmet Needs of the Pemphigus & Pemphigoid Community*. This “Voice of the Patient” report is a summary of the Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting on Pemphigus and Pemphigoid held on January 25, 2023. The meeting brought together patients and care partners, US Food and Drug Administration (FDA) representatives, pharmaceutical companies, doctors, and researchers. The goal of the meeting was to hear from patients about what it’s like to live with rare, autoimmune bullous skin diseases so that all involved can better understand the patient experience.

The “Voice of the Patient” report is designed to help the FDA make informed decisions about potential future therapies for pemphigus and pemphigoid. It can also help pharmaceutical companies design therapies and

clinical trials to address the aspects of these diseases that are most important to patients.

“Following 2023’s successful EL-PFDD meeting, the ‘Voice of the Patient Report’ is a critical next step in the IPPF’s engagement with the FDA and other decision-makers,” said IPPF Executive Director Patrick Dunn. “As we’ve learned, there are significant obstacles facing pemphigus and pemphigoid patients’ access to potential future therapies. To overcome these obstacles, we must empower the voice of a strong coalition of patients, caregivers, researchers, and clinicians so that regulatory agencies and industry partners understand what truly matters to people living with these diseases.”

This initiative was coordinated by a partnership of pemphigus and pemphigoid patient organizations, including the International Pemphigus & Pemphigoid Foundation (USA), PEM Friends (United Kingdom), Association Pemphigus Pemphigoïde France (France), and the Pemphigus/Pemphigoid Friends Association (Japan).

The Providing Realistic Opportunity to Equal and Comparable Treatment for Rare (“PROTECT Rare”) Act

The IPPF needs you to help ensure that individuals with very rare conditions like pemphigus and pemphigoid have the same intended benefit of health coverage as individuals with more common conditions—access to treatments our physicians know to be the standard of care for our medical conditions.

The bill will build on existing criteria for “medically necessary care” so that Medicare and Medicaid will be able to consider clinical guidelines and peer-reviewed literature to assess coverage of rare disease treatments.

HAYSTACK PROJECT
The Voices of Rare & Ultra Rare

HOW YOU CAN HELP

This is the opportunity we’ve been waiting for!

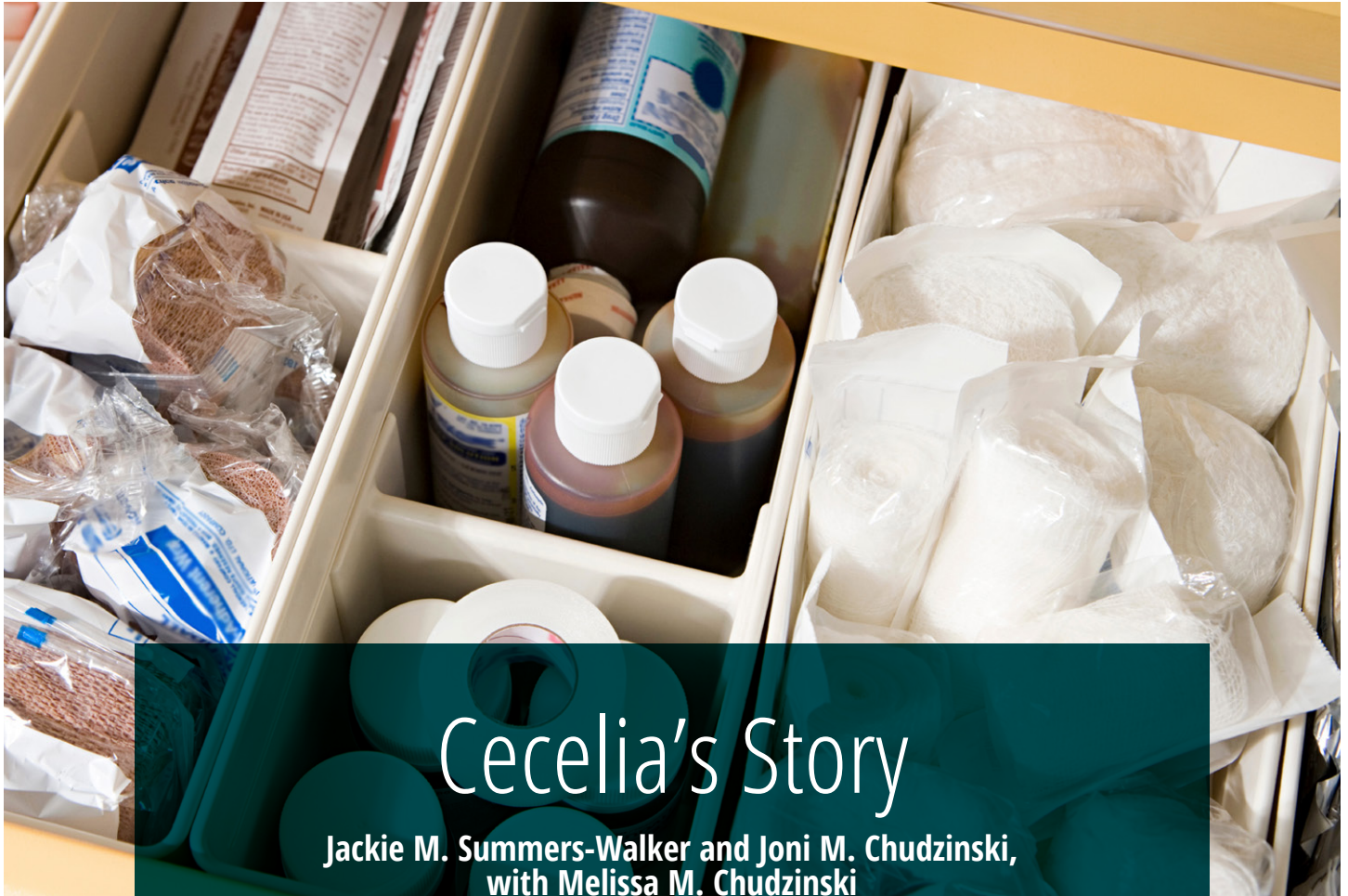
The U.S. House and Senate are considering The Protect Rare Act (H.R. 6094), a bill that will make it easier for rare disease patients to get the treatments our doctors say we need. It’s not about ‘special treatment’ for rare diseases. It’s about equal footing with those living with more common conditions.

ASK YOUR REPRESENTATIVE TO COSPONSOR THE BILL IN 2 EASY STEPS!

1. VISIT US ONLINE.
Visit <https://forms.gle/e1FZUCLJeDViFWVaA> and complete our form to send a letter to your members of Congress.

2. LET US TAKE IT FROM THERE!
We will get your communication to the right office and staff person, and we’ll also follow up with them too – so the time you take to help really does make a difference!

ACT NOW!



Cecelia's Story

Jackie M. Summers-Walker and Joni M. Chudzinski,
with Melissa M. Chudzinski

In loving memory of Cecelia M. Summers (1947–2022).

Our mother, **Cecelia**, suffered from bullous pemphigoid (BP) during the last few years of her life. The disease mostly affected her legs, but at times her entire body was covered with blisters and breakouts. The initial outbreak may have been stress-related, and likely most of her outbreaks were due to stress. Our mother noticed a blister on her right leg as her first symptom, which was the size of a softball. She never had a flare-up after her first blister since her blisters never went away. One blister would heal and immediately after, another would start, and she often had three or four blisters on each leg at a time. From the onset of our mother's diagnosis and throughout the rest of her life, there was not a

spot on her body that did not have a blister. During the summer months, she had blisters covering most of her body and she experienced immense pain.

She saw a dermatologist who was familiar with the disease but did not specialize in it. When we looked into finding her a different doctor, there were only two specialists located in our area (one had a disconnected phone number and the other doctor had a 10-month waiting list). So our mother faithfully saw her dermatologist, as well as a wound care specialist, who prescribed a combination of steroids and antibiotics. In addition, nurses came to her home every other day to change her bandages. We became her caregivers around the clock

to help change her bandages, assist her with medications, and check on her overall physical and emotional wellbeing. We cleaned her legs, covered the blisters with nonstick pads, and covered them with gauze pads because she was also allergic to medical tape. From the knee and below, both of her legs were covered with bandages that needed to be changed constantly. Her living room turned into what looked like a hospital room, and the amount of medical supplies she had in her home looked like a stock room at a doctor's office.

Our mother had an extensive medical history, with a hefty daily medication list, which is why she was unable to be prescribed anything for the pain associated with the disease. She constantly described her pain to us, and we did our very best to listen to her and help her as much as we could. She was able to take Tylenol, but she cried because her legs constantly hurt. The open sores put a constant damper on her life.

Our mother dealt with this every day, and she cried because there was never a resolution to it. She didn't go places because of her BP, and it definitely affected her life. We became our mother's nurses and joked that we were "Nurse 1" and "Nurse 2," which always made her laugh. We wished every day that we could have taken her pain away. We always tried to remain optimistic, because that's how we are, and we told her that someday she'd be fine again. But she never really was. It wasn't until about a week before her passing that her legs finally cleared up from the blisters. We were so happy for her. She was so excited that they were finally improving. Then, unfortunately, her comorbid medical conditions became worse, and she passed away.

It is important for people to become educated about and aware of BP, and hopefully there will be more dermatologists in the future that can specialize in it. If our mother had received more help and information about BP, it would have helped her and our family. Through telling her story and encouraging more awareness about BP, it will help others who have been impacted as well.

Our mother was a very sensitive woman who felt emotions deeply. Because of the constant BP outbreaks, she became increasingly sad and depressed. We wish we had been given more answers or help, and we hope as medical science continues to advance, that there will be more hope for others living with BP.

Our mother dealt with this every day, and she cried because there was never a resolution to it. She didn't go places because of her BP, and it definitely affected her life.

Cecelia was a kind and caring woman who truly wanted the best for everyone. In the later stages of her life, she was unexpectedly thrown curveball after curveball, but she tried to take it one day at a time. Receiving a BP diagnosis was something neither she nor our family expected. She experienced many difficult days but found her diagnosis bearable when she was able to process her feelings and emotions with others. Cecelia was known for more than just her illness; she was a loving mother, grandmother, daughter, sister, wife, and friend. She enjoyed the little things in life and was always there for others when they needed help. In Cecelia's memory, we hope to inspire others to take one day at a time. She understood the importance of continued BP research and speaking with others with BP to feel more connected and less alone, and for that, we share her story.

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Cecelia was diagnosed with bullous pemphigoid in the later stages of her life. Jackie M. Summers-Walker and Joni M. Chudzinski are two of Cecelia's daughters who helped Cecelia take care of her daily medical needs. Melissa M. Chudzinski is Cecelia's granddaughter, who volunteers with the IPPF.





Navigating Difficult Conversations with Your Physician

Samantha Herbert, Olivia Kam, and Renee Haughton

There are certain conversations that might seem embarrassing or awkward to bring up with your provider. Nearly everybody has experienced this at some point, and it is okay to feel uncomfortable. Remember, your provider wants to help you, and likely has these conversations daily.

How to talk about problems in private areas

Pemphigus and pemphigoid (P/P) often affect the genitals, chest, and buttocks. Providers understand that the physical exam of sensitive areas can be a vulnerable experience. Most will take extra precautions to keep you covered and limit the number of observers in the exam room. You are entitled to a chaperone, and some states in the US even mandate this.

Although your doctor is used to having these conversations, you may not feel comfortable, and that is okay. It may help to preface the conversation with a statement such as, “I feel nervous to talk about this.” Your doctor can then anticipate that a conversation about a sensitive

topic is approaching and can prepare to give you extra consideration.

How to talk about problems with your mental health

P/P have been shown to have significant effects on mental health and quality of life. Some providers will directly ask you about your mental health, coping mechanisms, and support system. It’s okay to say, “Doctor, I feel alone with this disease,” or, “I don’t feel like myself anymore.” Some signs of depression or anxiety may be less obvious: loss of appetite, having trouble concentrating, sleeping too much or too little, and experiencing tense muscles. Your doctor might not know you are experiencing any of these symptoms unless you bring them up. They can provide you with resources, such as referrals to a support group (including those run by the IPPF), psychotherapist, or psychiatrist. If the treatment plan is contributing to your stress, they may be able to work with you to make it easier.

How to talk about insurance and the ability to pay

Insurance plans are complicated, and your doctor might not know exactly how much your copayment might be. If a medication is too expensive, don't be afraid to ask your doctor if there is something they can do. Doctors deal with this all the time, and sometimes they can write what is called a prior authorization to your insurance to get the medication covered. Another option is utilizing coupons from GoodRx, a free service that offers reduced prices for many medications, although you cannot use these coupons in conjunction with discounts or copays from your insurance. They can also consider other treatment options that may be more affordable. Although your doctor and their team may not be able to help you access all medications at a low cost, they will help you tailor a plan that fits within your budget as best as they can.

How to bring up accommodations or disability

Symptoms of P/P may prevent you from being able to work. Although bullous diseases sometimes qualify patients for Social Security Disability Insurance (SSDI), it can be a long process and difficult to get approved. Accommodations at work may also be available. If working has been difficult because of your disease, open the conversation with your doctor directly. A prompt may sound like, "Going to work has been difficult for me. I have been thinking about applying for accommodations/disability benefits. I'd like to hear your thoughts."

If applying for SSDI, your doctor will need very detailed information about your limitations for their letter. The decision to apply is a personal choice based on a variety of factors. Your doctor can discuss your options and chances of receiving benefits and can help you decide whether you want to proceed.

How to discuss if you feel your doctor is not listening to you

Sometimes you might feel that your doctors don't respond to your needs. Luckily, there are many ways you can help your provider improve. For example, if the care didn't meet your expectations, you can tell your doctor, "I feel like we went through my treatment options too quickly. Can we go over them again? I still have questions." Most doctor's offices also have paper or post-visit email surveys for delivering anonymous feedback if that feels more comfortable. Ask the front office or check

the waiting room. Remember, your feedback will bring attention to ways that the healthcare team can not only improve your care but also the care of other patients.

Visits are often fast because of all the people who need care from a dermatologist. The most urgent problems are often addressed, but both a provider and a patient may have topics they want to explore further. Ask for closer follow-up visits so you can continue discussing other topics that weren't fully covered.

General Reminders

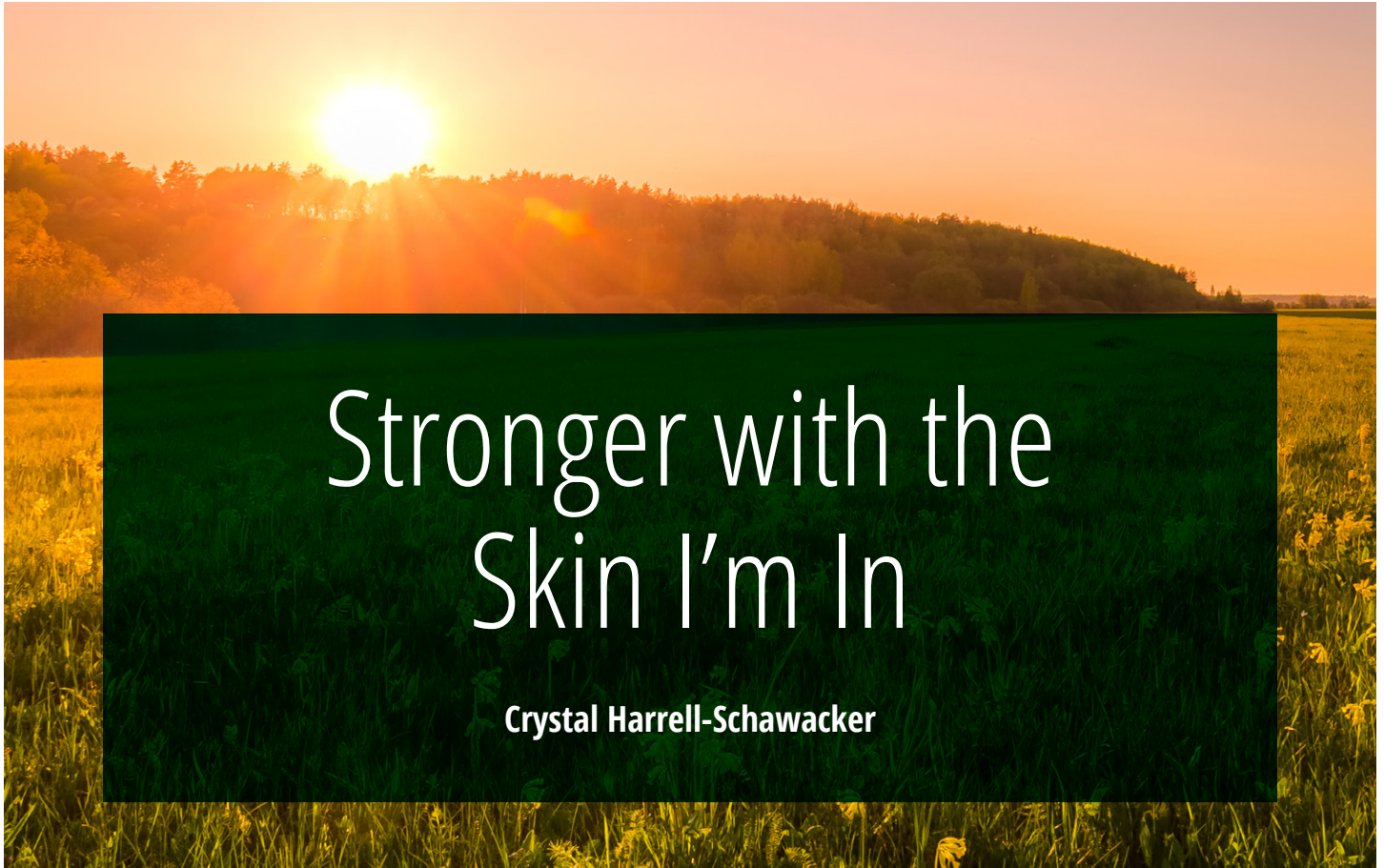
No matter what the situation is, here are some good reminders for approaching potentially difficult conversations:

- Write your questions down. Medical appointments can go by quickly, and it is hard to find the right moment to ask your question. Ask your questions! Even if it feels irrelevant, your doctor can tell you whether they think it might be related to your skin disease or one of your treatments.
- Decide ahead of time who you want in the room with you. Maybe your family member always travels to your appointments with you, but you can ask them to sit outside for all or a portion of the visit. Although it is helpful for medical trainees (future providers) to be a part of physical exams, you are welcome to ask them to leave to limit the number of people in the room.
- You have the privilege of a confidential doctor-patient relationship. A physician is bound to keep everything that you say to them private unless there is an imminent concern for harm to yourself or others.

Samantha Herbert, MSPH, is a fourth-year medical student at the University of Miami Miller School of Medicine. She is interested in immune-mediated skin diseases and community engagement.

Olivia Kam is a third-year medical student at Stony Brook School of Medicine. She is interested in immune-mediated skin diseases and skin of color.

Renee Haughton, MD, is a clinical research fellow at the University of California, Davis Department of Dermatology. She is interested in complex medical dermatology.



Stronger with the Skin I'm In

Crystal Harrell-Schawacker

2016 was shaping up to be a very important year. I had just received my associate degree in journalism and was all set to transfer to a four-year university in the fall to pursue my bachelor's degree. On top of that, I turned 21 in February and was looking forward to savoring all of the exciting things young adulthood had to offer. It was during this same month that everything changed.

I noticed a few innocent-looking blisters on my nose that were fragile to the touch. Although this was something I had never experienced before, I thought nothing of it and waited for the broken skin to heal on its own. It never did. The following weeks showed a worsening of my then-unknown condition: The taste of blood and large blotches of red in the sink were always present after brushing my teeth, the open sores on my face had multiplied to startling numbers, and the skin on the rest of my body threatened to tear away with any slight use of force or friction.

By this point, I had seen my dentist and three different dermatologists, none of whom could provide me with a direct answer as to what exactly was wrong with me. The dentist blamed my symptoms on neglectful hygienic practices, and the others deemed it as an aggressive form of acne before prescribing me various ointments and creams to slather on my face. Weeks of waiting to see improvement turned into months, and the sores that started on my face were also manifesting on my chest and back. My appointments with the dermatologist were beginning to feel as unreal as an episode of *The Twilight Zone*, with no one able to fully respond to my questions, while exposing me to different kinds of light therapy, promising no results but always willing to prescribe more pharmaceuticals.

By the time May came around, I was living in a horror film. Mornings began with my skin peeling away with the slightest touch and my clothes sticking to the popped blisters that covered my body. My days were plagued by the excruciating pain of exposed flesh, my wavering faith



Sometimes life can throw the most unexpected challenges at us, but we must carry on with the comfort that there will be better days ahead.

of recovery, and the growing fear of the unknown.

When it was time to sleep, I dreaded waking up to see what new bodily wound awaited me in the morning. I began to think, “*Will I ever be the same again?*”

I had decided that instead of waiting around for empty promises to be fulfilled, I needed results. Taking matters into our own hands, my mother and I researched my symptoms and visited a contagious disease specialist. Still clueless as to what ailment was literally tearing me apart all those months, I had come to believe it was something I caught from an outside source.

When the specialist analyzed my skin biopsy, he told me what I had was not an infection, but an autoimmune disorder called pemphigus vulgaris (PV).

Initially, I was shocked when I found out it wasn’t a foreign bacteria or severe allergic reaction that was ravaging my skin—it was my own body turning against me. Being given this surprising diagnosis has taught me to never take my health for granted, and even though I have improved significantly since that fateful day in May, I am still on the mend and learning to cope with the healing process of my condition.

Through this long journey, I have learned valuable lessons regarding myself and what truly matters in life. Whether you have a blistering autoimmune disorder or any other visibly noticeable condition, it does not matter what other people think of your appearance. They will never know the challenges you’ve faced and the battles you’ve won. The best part is knowing that you have survived through it all and are stronger because of the hardship.

Without a doubt, some days will be better than others, but when you feel you are being overpowered by those

negative emotions, remember to surround yourself with love. I am immensely grateful for the support and care my loved ones have shown me, especially my parents, who have been by my side at every doctor’s appointment, from the Coachella Valley all the way to San Bernardino, California. They are the light that still shines on my darkest moments. Even if it’s a hobby or a friend to talk to, find what gives you joy and hold onto that feeling. Happiness is the strongest medicine, and you deserve to feel your best even when your situation may not be.

Finally, the most important lesson that I’ve realized is that you know your body better than anyone else. If you encounter a physician that does not satisfy your concerns or answer important questions you have, do not settle; seek the help you need until you find a doctor you feel confident will listen to you. I spent months misdiagnosed and being treated as though my observations and concerns weren’t relevant. When you know something is deeply wrong, you should always have the full support of a physician who has your best interests in mind.

Sometimes life can throw the most unexpected challenges at us, but we must carry on with the comfort that there will be better days ahead. Despite needing to undergo Rituxan® infusion therapy multiple times in a year, I am currently working full time as a promotions producer at a television news studio, with no intention of letting my condition get the best of me. My body may be at war with itself, but I know I’ll come out victorious in the end.

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Crystal Harrell-Schawacker was diagnosed with PV at the age of 21 and has spent her young adult life navigating the ups and downs of her condition while maintaining a professional career. Writing has always been her way of coping with PV, and she has written various articles detailing her medical journey in publications like the IPPF blog PemPress, Desert Health, and Coachella Valley Independent.



JOIN THE MOVEMENT

It's About Our Skin, But
It's Also About Our Lives

The World Skin Health Coalition is a patient-led multi-stakeholder group of patient organizations, health care professional societies, industry companies and research organizations. Together, we're embarking on a mission that's about our skin and so much more. Our goal? To raise global awareness about the profound impact of skin diseases, and to urge health policy leaders worldwide to prioritize these critical issues.

But we can't do it without you. Help us reach policymakers by signing our open letter.

By signing our open letter, you're advocating for a future where skin health is given its due importance – where every individual dealing with a skin condition or disease receives the care, respect, and attention they deserve.

SIGN THE OPEN LETTER AT
NotJustMySkin.org



Peer Coach Spotlight: Marc Yale

Our Peer Coach Spotlight section features one of our IPPF Peer Coaches, volunteers who have learned to manage living with pemphigus and pemphigoid (P/P). Peer Coaches share their personal tips and tricks, as well as IPPF resources and educational materials that help people affected by P/P to have meaningful discussions with their healthcare teams. Learn more at pemphigus.org/peer-coaches. This issue, we asked Marc Yale to share more about himself.



Marc Yale was diagnosed in 2007 with mucous membrane pemphigoid (MMP). Like others with a rare disease, he experienced delays in diagnosis and difficulty finding a knowledgeable physician. Eventually, Marc lost the vision in his left eye from the disease. This inspired him to help others with P/P. In 2008, he joined the IPPF as a Peer Coach, working with people to improve their quality of life and encouraging them to become self-advocates. In 2009, he helped develop the Pemphigus and Pemphigoid Comprehensive Disease Profile giving experts insight into the patient perspective.

In 2016, Marc became the Executive Director of the IPPF. He currently serves as the Advocacy & Research Coordinator of the IPPF so that he can focus on research and advocate for all of those affected by P/P. He was invited to serve on the Patient-Centered Outcomes Research Institute (PCORI) Rare Diseases Advisory Panel, is a member of the American Academy of Dermatology Drug Transparency Task Force, sits on the Executive Board of Directors for The International Alliance for Dermatological Patient Organizations (GlobalSkin) as their President, serves on the Board of Directors of Haystack Project, and is a committee advisor for Rare Disease Legislative Advocates.

Last year, Marc joined Rare Disease International in the establishment of the WHO Collaborative Global Network for Rare Diseases Panel of Experts to ensure a lasting impact on the lives of people living with a rare disease around the globe.

How did you become involved with the IPPF?

When I was diagnosed in 2007 with MMP, I found the IPPF through a Google search and tried to learn as much as I could about the disease. Although it had only taken six months for me to get diagnosed, the delay had taken a huge toll as I lost the vision in my left eye. I was astonished that more doctors didn't know about this disease and felt compelled to create more awareness. I contacted the IPPF, joined the discussion group, looked for more doctors to add to the website, attended a Southern California support group meeting,

and traveled to the Annual Conference in Dallas, Texas. Once I met others like me, I became inspired to volunteer as much time as I could during my recovery to help others that suffer from these diseases.

What is something that our community members with P/P can do to better advocate for themselves?

Remember that your experience is unique and that you are the expert in your disease. Don't be afraid to speak up and share your experience. I recommend that everyone learn as much about the disease as possible. There are many resources available and the more that you know the easier it will be to advocate for yourself. You can get your disease under control by taking control of your health.

Which treatment(s) did you take in your rare disease journey?

Initially, I was prescribed a high dose of prednisone (120mg) and topical treatments for my mouth and skin lesions. Afterwards, I was given Dapsone, which after six weeks caused severe anemia. I was then prescribed Azathioprine, which was also ineffective. My doctor switched me to Cyclophosphamide, and I unfortunately landed in the hospital with pneumonia from extreme immunosuppression. Finally, I was prescribed IVIG and rituximab, which helped me reach my first remission. I was also on various antibiotics and vitamin supplements throughout my disease journey.

What is something fun or interesting about yourself?

My first volunteer work was with the American Red Cross 39 years ago as a Fire Camp Coordinator during the wildfires in nearby cities.

A Tribute to Doctors

Janet Segall

When I started the IPPF in 1994 I was lucky to find Greta Clarke, MD, who at least knew what pemphigus vulgaris (PV) was even though she had never treated it before. She had completed her residency at New York University (NYU) where she had seen some patients with PV. At the time, doctors would not always take MediCal (Medicaid in California) and initially, the doctors I saw didn't let me have a voice in my care. Dr. Clarke helped me a lot on my path to recovery and I thank her for agreeing to see me as a patient for a reduced rate since she wasn't taking Medicare and MediCal at that time. When I explained to her that my six-year-old daughter was having a hard time with my diagnosis, she told me to bring her in to see her. She told my daughter that I wasn't going to die, gave her personal phone number to her, and told my daughter to call her anytime she needed to. My daughter put the card in her dresser drawer, and the main problem she was having stopped. I was so grateful to Dr. Clarke for her kindness and thoughtfulness.

In order to fulfill my vision of starting the Foundation, I knew I needed help from a medical expert. I wrote many letters to several doctors whose names I found on papers at the National Institutes of Health (NIH).

In order to fulfill my vision of starting the Foundation, I knew I needed help from a medical expert. I wrote many letters to several doctors whose names I found on papers at the National Institutes of Health (NIH), and finally John Stanley, MD, who was Head of Dermatology at the University of Pennsylvania in Philadelphia, wrote back to me and suggested I contact Grant Anhalt, MD, at Johns Hopkins University in Baltimore. When I contacted Dr. Anhalt he was very interested.

It was lucky that I and my three Board of Directors members got to meet him at the American Academy of Dermatology meeting, which was in San Francisco that year. I was living in Berkeley, California, at the time so it was close by. We got together one evening at a restaurant in San Francisco, and Dr. Anhalt was skeptical. He said that he had met other people who wanted to start a foundation but it never went anywhere. He didn't know me, but I must have convinced him that I was serious. With his help (the internet was still in its infancy), I put together a database of dermatologists and sent them letters (with my signature and Dr. Anhalt's) to let them know that a foundation existed for patients.

Dr. Anhalt put together our first Medical Advisory Board with some of the leading bullous disease specialists in the country, including Dr. Stanley; Luis Diaz, MD, (University of North Carolina); Robert Jordon, MD, (University of Texas, Houston); and Jean-Claude Bystryn, MD, (NYU). Later, Victoria Werth, MD, (University of Pennsylvania) and Sergei Grando, MD, PhD, (University of California, Irvine) joined the Medical Advisory Board as well.

With the help of our Medical Advisory Board, other doctors became interested. They were willing to work with us now and they spoke at support group meetings or at our annual meetings. We developed science-based

meetings with doctors who supported us from around the world—England, France, Germany, the Netherlands, Japan, Italy, Israel, Australia, and Switzerland. Many of these countries now have support groups of their own. Most of these meetings consisted of doctors and researchers speaking about the science of pemphigus and pemphigoid (P/P). We let them know how important it was for patients to speak about living with P/P to show them the human side of our diseases. The medical and science side of P/P is important, but there are human beings living with these diseases that are greatly affected. Currently, both the human and science sides of P/P are typically discussed during these meetings.

In addition, the IPPF spoke about P/P at the American Academy of Dermatology (AAD) annual meetings, and for several years, we were given a free exhibit table at the meeting. Eventually, we displayed together with the Coalition of Skin Diseases at the AAD meetings.

I also would like to recognize Stephen Katz, MD, PhD, who was the Head of the National Institute of Arthritis, Muscular and Skin Diseases (NIAMS) at the NIH. Unfortunately, he has since passed away, but he was always very supportive of the IPPF and P/P researchers. He was presented with an award at the annual meeting we held in New York.

After starting the IPPF, I visited England, France, Israel, and Italy to assist the international support groups. I found that the doctors were more than willing to be a part of the Foundation and encourage the support groups. During my last trip to Europe, I was giving a presentation about the IPPF at a Scientific Meeting in Switzerland, and I was given a tribute. This touched my heart since I was planning a leave of absence from the IPPF for a few years.

When I returned to the Foundation as a Peer Coach, more bullous disease specialists had joined our Medical Advisory Board. There were also additional doctors across the US and internationally that we were able to



Janet Segall, Dr. Grant Anhalt, and Marc Yale at the 2018 Patient Education Conference Award's Ceremony where Dr. Grant Anhalt was recognized with the Founder's Award.

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add to a list to provide to P/P patients that were seeking care. Our doctor list has evolved and is accessible on the IPPF's website at pemphigus.org/find-a-doctor. In addition to P/P doctors, there are also amazing researchers across the world doing wonderful work in finding better P/P treatments and/or a cure.

I am so proud to be a part of the IPPF and I'm thankful for the wonderful caring doctors who help us find our way through P/P. They have made it possible for the IPPF to continue to give patients the help and care they need. I send each and every one a deep thank you!

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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.



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