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Message from the Executive Director

Dear Reader,

Much of the work we do at the IPPF involves patient stories. We talk about the often winding and difficult journey from symptom onset to diagnosis, through multiple treatments and phases of disease management that may, hopefully, lead to remission. Over my time at the IPPF, I've read or heard hundreds of stories from people affected by pemphigus and pemphigoid (P/P). One thing that strikes me is that for such rare conditions affecting such a wide variety of people, many of these experiences share a similar story arc.

First, there's the delay in receiving a correct diagnosis. As symptoms persist, many remain undiagnosed or misdiagnosed for months or years, resulting in worsening symptoms and delays in receiving effective treatment. Then, there's finding a medical team who is not only familiar with P/P, but also knows how to treat them. Once the right doctors are found, patients often need high levels of medications to get their disease activity under control. By this point in the story, many patients have also been fighting with insurers or payers for approval of off-label therapies, which in and of itself is a frustrating subplot.

The most heartening of these stories end with either complete remission, or at least a level of disease activity that allows the patient to enjoy a quality of life similar to their pre-disease days. I will also acknowledge my own bias as I add that I'm particularly fond of the stories that illustrate how the IPPF helped to improve a patient's quality of life.

If this all seems like an oversimplification of a years-long, life-changing struggle, that's because it is. The real point I'm trying to make here is that even though I know how these stories usually go—where the plot will thicken and how the hero will struggle—I'm deeply and emotionally impacted by each one. This is as true for the 301st story as it was for the 1st, and it will continue to be true for as long as patients are willing to share their stories. The reason for this is that you—the person affected by P/P—are unique, and your story is powerful. You are more than your disease journey. In fact, this particular story is just one of the thousands that make up the chapters of your life.

Throughout this issue of the Quarterly, you'll find a number of personal experiences that illustrate how powerful sharing your story can be. You'll find patients and caregivers sharing their experiences and lessons learned. You'll also hear from the other side of the stethoscope: medical and dental professionals and students sharing how patient stories have a major impact on their work and that of their colleagues. You'll even find a recap of the World Congress of Dermatology in Singapore, at which IPPF Research and Advocacy Coordinator Marvell Adams became the first skin disease patient to be invited to give a keynote address—all from the power of sharing his story!

So, if you've ever shared even a piece of your story publicly or in private, thank you. You never know how this chapter of your life could change the trajectory of someone else's story.

Patrick Dunn, IPPF Executive Director
patrick@pemphigus.org
Medical education is a journey of continuous learning, where aspiring doctors equip themselves with the knowledge and skills required to provide optimal patient care. Medical students are exposed to a tremendous number of diseases and conditions in their curriculum, but the rare and less understood ones often receive less attention. Organizing presentations featuring patients with rare diseases can be an invaluable experience, offering unique insights into the lives of those affected and their diagnostic journeys.

On May 5, 2023, the University of Central Florida (UCF) College of Medicine hosted a presentation led by IPPF Outreach Director Becky Strong about her experience being diagnosed and living with pemphigus vulgaris (PV). Becky spoke to a group of medical student members of the UCF Dermatology Interest Group (DIG), elaborating on her long, complicated diagnostic journey. Though most of the students in attendance were familiar with PV, at least from a pre-clinical perspective, every student was astonished by the amount of time it took for Becky to receive a final diagnosis. In our coursework, we were told that a PV diagnosis is made through direct immunofluorescence (DIF) taken from a biopsy of the affected tissue. However, we were not taught how the decision to perform a biopsy is made, what patients’ primary concerns

Though most of the students in attendance were familiar with PV, every student was astonished by the amount of time it took for Becky to receive a final diagnosis.
may be, and what the practical obstacles are in obtaining a biopsy. Becky’s story of moving from clinician to clinician before finally finding someone who was curious enough to complete a biopsy highlighted to us the importance of asking questions and listening to the patient’s entire story.

One point that Becky made really resonated with our students. She shared how her concerns with eating were routinely dismissed as being related to her hygiene, rather than another underlying condition. One student who attended our presentation found that part of her story particularly shocking, because clinicians should not stigmatize patients unfairly but assume the best of the people they are treating.

In medical school, especially during the pre-clinical years, medical students learn about the foundational science of medicine largely through the lens of biochemical and physiological processes. This provides a solid framework for learning the function of the human body and disease progression, but understanding the patient experience usually comes much later in the curriculum. For this reason, it is essential for us to hear the perspectives of people like Becky who can give a firsthand account of the challenges of living with a rare disease. It is a privilege to learn about a clinically interesting condition like PV directly from someone who is living with it.

In addition, having compassion and empathy for patients is one of the key competencies of the role of physicians, and opportunities like this can help us understand patients’ difficulties in a way that cannot be taught in a traditional classroom setting. It’s worthwhile for medical students, residents, and even other doctors to be reminded of what they are studying and of the broad world of dermatologic illness. Some conditions, like PV, are often overlooked and take an extremely long time to diagnose. Even as students, we appreciate the chance to learn about opportunities to improve patients’ lives in ways that are immediately actionable, as well as keeping these experiences in mind as we work toward becoming attending physicians.

It was an honor for us to host Becky and have her speak so openly and honestly about her life with PV. It is a rare privilege to learn from someone who lives with this condition every day, and it elevates our understanding of the condition far beyond what we would have gained from a textbook entry. As medical students interested in dermatology, we try to familiarize ourselves with the various pathologies and treatments within dermatology as best as we can. In pursuit of this, many of us pursue biomedical research and present at meetings. However, it is far more rewarding and meaningful to ask someone living with such a condition how their life has been affected than to simply read about associated symptoms.

It is essential for us to hear the perspectives of people like Becky who can give a firsthand account of the challenges of living with a rare disease.

This patient-led presentation created newfound interest in pemphigus and pemphigoid (P/P) amongst our students. Many of the medical students in DIG have since begun to dive deeper into autoimmune diseases such as P/P, especially in the realm of research and clinical advocacy. Our students benefited immensely from having Becky speak at UCF College of Medicine, and we would strongly encourage more medical schools to invite patient advocates from the IPPF to deliver similar presentations. As medical education evolves, incorporating patient perspectives should become a fundamental aspect of the curriculum, empowering future doctors to embrace the rare and deliver personalized, compassionate care to all patients they encounter in their careers.

Sean Ojha is a second-year medical student at the University of Central Florida College of Medicine with an interest in autoimmune disease and dermatology.

Elizabeth Durkin is a second-year medical student at the University of Central Florida College of Medicine with an interest in surgical dermatology.
Q4HE Collaborates with Western University of Health Sciences to Support Biopsies Save Lives

This press release was originally published by Quest Diagnostics on July 20, 2023.

Quest Diagnostics, through the Quest for Health Equity (Q4HE) initiative, has teamed up with Western University of Health Sciences (WesternU) to offer no-cost diagnostic testing services to support Biopsies Save Lives. This multidisciplinary program will offer no-cost testing to patients in Southern California who are low-income, uninsured, and underinsured and who have rare erosive and blistering diseases, to enable more timely diagnosis of these conditions.

Pemphigus and pemphigoid are rare autoimmune diseases that are potentially fatal if undiagnosed or untreated. People with these diseases must often see multiple healthcare providers before seeing a specialist and receiving a diagnosis. People of color are more likely to be misdiagnosed or experience delays in diagnosis because differences in pigmentation can affect the appearance of dermatologic diseases.

“The time it takes to get a correct diagnosis can be critical for people who are working-class or living in poverty. Compounding this, people of color are more likely to have delays in diagnosis because pathologic conditions can manifest differently on dark skin and mucosa, and healthcare professionals are trained mostly to diagnose them on white patients,” said WesternU Health Oral Pathology Laboratory Director Mark Mintline, DDS. “We are grateful for the support from Quest and its Quest for Health Equity initiative, as it will help eliminate a barrier to diagnosis and enable us to expedite the treatment of patients suffering from these diseases.”

The collaboration between Q4HE and WesternU, with additional support from the International Pemphigus and Pemphigoid Foundation (IPPF) and the University of California Irvine (UCI) Health Dermatology Immunobullous Clinic, aims to accelerate dermatology diagnosis times and help reduce the number of doctors needed to get a diagnosis. Local healthcare providers will be able to refer patients for intraoral biopsies and serum testing without worrying about the cost of laboratory tests thanks to no-cost diagnostic testing provided through the Q4HE initiative.

“We believe good healthcare should be in reach for everyone, and we are proud to support this important program to give access to lab testing that will help provide care to underserved patients in Southern California suffering from these rare autoimmune diseases,” said Michael Floyd, Senior Director and Leader, Q4HE. “We are hopeful that we can help break down some of the barriers to healthcare access that these patients are experiencing by making diagnostic testing more accessible.”

Biopsies Save Lives also connects patients to the IPPF, which offers peer coaching, patient education webinars, support groups, publications, and a network of doctors who are experienced in treating pemphigus and pemphigoid patients. This includes expert dermatologists from UCI Health Dermatology, which specializes in the diagnosis, treatment, and management of acquired autoimmune blistering diseases. WesternU also provides medical interpreters to facilitate communication between patients, doctors, and staff to ensure high-quality care.

To learn more about the Biopsies Save Lives program, visit www.pemphigus.org/biopsies-save-lives/.
Diagnosed with **Bullous Pemphigoid**? (BP)

**Learn about a study of a potential new treatment for BP**

With your participation, you can help researchers investigate a potential treatment for BP

**ballad**

Bullous Pemphigoid Study

**Who Can Take Part?**

- 18 years old+
- Confirmed diagnosis of moderate to severe BP
- Active blisters
- There are additional study requirements you must meet to take part in this study. A study representative will discuss these with you.

**What Will The Study Involve?**

- Screening period: 2-3 weekly visits
- 43 weekly visits – most at the study center, some at home
- 1-2 minute subcutaneous injection (under the skin)

**Are There Any Costs?**

- No costs to participant
- Travel, accommodations, food and drink expenses reimbursed by study sponsor

**How Do I Participate?**

The first step is to talk with your doctor and share the study listing:


Speak to a Know Rare Patient Advocate who can help you connect to a study center to discuss the details of the study and if you are eligible to participate.

Go to [balladstudybp.com](http://balladstudybp.com)

IPPF VIRTUAL PATIENT EDUCATION CONFERENCE

OCTOBER 27-29

EMPOWERING THE PATIENT VOICE

CONFERENCE TOPICS

- Pemphigus and Pemphigoid Disease Overview and Subtypes
- Newly Diagnosed, Now What?
- Mental Health
- Steroids
- Biologic Agents- IVIg and Rituximab
- Nutrition
- Caring for Your Skin and Wounds
- Making Informed Decisions with Your Healthcare Provider
- Medicare Open Enrollment
- Advocating for Policy Change
- Immunosuppressive and Anti-Inflammatory Agents
- Biosimilars
- Oral Disease and Care
- New Treatment Strategies for Ocular Disease
- Connecting with the Community
- Emerging Therapies in Pemphigus and Pemphigoid
- Patient Data and Drug Development
- Clinical Trials
- Co-pay Assistance

GO.PEMPHIGUS.ORG/CONFERENCE2023
The IPPF Attends the 2023 World Congress of Dermatology in Singapore

Marc Yale

The World Congress of Dermatology (WCD), held every four years, is one of the largest international dermatological conferences. It is organized in conjunction with the International League of Dermatological Societies (ILDS) and was held this year from July 3-8 in Singapore. I was proud to actively participate in the WCD this year and represent the IPPF community as well as our strategic partner, GlobalSkin.

The WCD emphasizes the science and practice of dermatology for specialists from around the world, showcases new knowledge, clinical experience, scientific research, and builds professional and personal networks and collaborations. Over the past 130 years, the WCD has brought together dermatologists and professional societies and has promoted the importance of skin health and skin diseases.

By far, the highlight of the WCD for me was being invited to present as a keynote speaker about the “Global Cooperation in Elevating Medical Dermatology.” This was quite a monumental occasion because, for the first time in the history of the WCD, a skin disease patient was given the opportunity to be a keynote speaker. I was honored to represent the over 100 million people living with skin diseases around the globe.

Another high point for me was having the opportunity to meet other patient organization leaders from around the world, many of them patients themselves. The IPPF participated in the Patient and Dermatology Community Village and shared resources about our Biopsies Save Lives Program. I attended a symposium on “Building Impactful Patient Organizations through Supportive Partnerships,” where the objective was to bring together the dermatology community to explore how to foster effective interactions and collaborations to support the establishment and growth of dermatology patient organizations. It was a huge success with over 55 patient leaders in attendance!

I also participated in an Expert Forum called “Patients as partners in advancing dermatology through research and advocacy.” The session was attended by dermatologists, industry partners, and patient advocacy groups. Many patient support organizations, especially in Asia, have significant challenges supporting people with skin diseases. I was able to share the history and success that the IPPF has had in establishing an effective support organization and emphasize our mission to improve the lives of all those affected by pemphigus and pemphigoid. I also stressed that patients are “patient experience experts” and the patient experience is what drives qualitative research, qualitative data collection, and ultimately better health outcomes. Only the patients have authoritative knowledge about living with their disease and they need to be listened to and heard. I was able to share my personal experience and knowledge to support others so they can better understand these diseases.

Overall, the IPPF was able to successfully connect with bul- lous disease experts and patient organizations, to network with healthcare professional delegates, and to advocate for the patient voice at this important dermatological event. We continue to lead the way in voicing the needs of the pemphigus and pemphigoid community and promote the work GlobalSkin* is undertaking to elevate the understanding and prioritization of dermatological diseases.

*The International Alliance of Dermatology Patient Organizations (also known as GlobalSkin) is a unique global alliance serving patient organizations to improve the lives of dermatology patients worldwide. Learn more at globalskin.org.

Marc Yale was diagnosed in 2007 with cicatricial pemphigoid. In 2008 he joined the IPPF as a peer coach. He was the executive director from 2016-2020 and is now the research and advocacy coordinator. Marc currently resides in Ventura, CA with his wife Beth and his daughter Hannah.
Helping Caregivers of Loved Ones with Pemphigus and Pemphigoid Avoid Caregiver Burnout

Marvell Adams, Jr.

What is caregiver burnout?

The fact that caregiving can be stressful is nothing new. You may feel that no matter what you do, it’s not enough, or everything is on your shoulders. You may feel overwhelmed, anxious, or frustrated. If you don’t address it, this stress can lead to caregiver burnout over time.

Many aspects of caregiving for a loved one can lead to burnout. You may feel other family members aren’t helping as much as they should be. There’s just too much to do and not enough time to do it. Once your loved one finally gets a diagnosis, there are all the doctor appointments—often requiring travel to a major teaching hospital to see a specialist—and the time it takes to help your loved one with things like dressing changes. With all the demands on your time, you may not have any time for yourself.

The pain and discomfort that comes with pemphigus and pemphigoid may cause your loved one to be depressed, disagreeable, and withdrawn from the outside world. This isolation can carry over to the caregiver, leading to depression and other symptoms of burnout. As a caregiver, you may have unreal expectations. In a perfect world, with you as a caregiver, your loved one would get treatment and recover completely. Sadly, life doesn’t always work that way. You may feel afraid and have feelings of uncertainty about the future. You may feel guilty, thinking you should be doing more, or neglecting other family members.

Caregiver burnout can affect your mood and make you tense, angry, anxious, depressed, irritable, frustrated, or fearful. It can make you feel out of control, helpless, unable to focus, or lonely. Caregiver burnout can also cause physical symptoms such as trouble sleeping, muscle tension (back, shoulder, or neck pain), headaches, stomach problems, weight gain or loss, fatigue, chest pain, heart problems, hair loss, skin problems, or colds and infections.
How to prevent caregiver burnout

- Talk to someone you trust about how you’re feeling—a friend, another family member, a counselor, or clergy member.
- If someone offers to help, let them. Make a list of errands or tasks someone else can do.
- Pay attention to your mental health. Depression and anxiety often come along with caregiving. Seek help if you need it.
- Try to find time for yourself. That may mean getting up 20 minutes early so you can have time to have a cup of coffee, read a chapter of a good book, take a walk, or do any activity that makes you happy.
- Stay healthy by eating a balanced diet, staying hydrated, exercising, and maintaining healthy sleep patterns. Don’t neglect your own doctor’s appointments.
- Accept that you may need help and ask for it. Asking for help is not a sign of weakness.
- Educate yourself about your loved one’s disease or condition. Knowing what to expect may ease some of your anxiety and uncertainty about the future.
- Join a support group. Some support groups are condition-specific, relationship-oriented, or for a specific demographic. Talking to people who have gone through similar challenges and sharing your experiences can make a difference. You are not alone and should not feel as though you are.
- Plan for legal or financial issues that may come up later. If you plan now, you’ll have less stress later on.

What to do if you are experiencing caregiver burnout

The Caregiver Action Network (CAN) is here to help you. CAN is the nation’s leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with significant health needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of multiple sclerosis (MS), to adult children caring for parents with Alzheimer’s disease.

The CAN website (caregiveraction.org) offers many ways to address caregiver burnout.

It can help to talk to people who have gone through a similar experience as you.

- Contact CAN’s free Caregiver Help Desk. The Help Desk is staffed by caregiving experts who can support you, answer questions, help you find information, or be there to listen. You can contact the Help Desk by phone, email, or live chat Monday-Friday from 8 a.m. to 7 p.m. Eastern time.
- Find the right support group. It can help to talk to people who have gone through a similar experience as you. You can share what you’ve learned and get tips from other caregivers. You can find support groups that are specifically for your loved one’s condition or disease, ones that are for spouses or other relationships, or ones for different targeted groups.
- Take advantage of respite care services. There will be a time when you need to take a break. Contact respite care services and arrange for someone to care for your loved one while you refuel.
- If you are depressed, seek help from a mental health professional who is used to dealing with depression, such as a therapist, psychiatrist, psychologist, or licensed social worker.

Caregiver burnout resources

- Finding the right support group (caregiveraction.org/finding-right-support-group)
- Coping with time demands (rarecaregivers.org/time-demands)
- Caregiver Action Network: 10 Tips for Family Caregivers (caregiveraction.org/resources/10-tips-family-caregivers)
- Legal and financial tools (caregiveraction.org/resources/financial-and-legal-tools)

Marvell Adams, Jr. is CEO of Caregiver Action Network. He is a highly skilled and passionate advocate, educator, and leader with a lifelong commitment of service to caregivers, marginalized communities, and older adults. Diversity, equity, inclusion, belonging, and accessibility are a central theme in all aspects of Marvell’s work with a tireless devotion to creating equity in caregiving for all.
I credit my wife, Carol, for my ability to make it through my journey with pemphigus vulgaris (PV). I would not have made it without her and our support network. While I probably would have survived physically, I doubt I would be the same spiritually. Thanks to her, I could rely on a support network. I realized how important it is not to be alone while facing a health challenge. Since then, I have been willing to respond to anyone else who contacts me about their ordeal.

A few years before my diagnosis, we moved to San Francisco for new jobs. I met a board member of the institution I was heading who had survived cancer. He and his wife wrote a book about their ongoing endeavor. In *The Power of Two: Surviving Serious Illness with an Attitude and an Advocate*, they described in detail how they fought the disease. I skimmed the copy he had gifted us, and I was inspired in the abstract—without any sense that what he was discussing would apply to us as well. Encountering him was a harbinger.

To start, my wife insisted I not ignore the issue. I had what I thought might be bed bug bites from a trip to New York City. Then my primary care physician diagnosed, erroneously, eczema, from which I had been vexed intermittently throughout life. I tried creams and salves to no avail. Carol was skeptical. She said I must look for specialists. To satisfy her, I kept making appointments to figure out what was going on.

By coincidence, Carol herself had to address a problem. She has osteoporosis, rheumatoid arthritis, and lupus. She was scheduled for anterior cervical discectomy and fusion (ACDF) to remedy problems with a total of three vertebrae. The surgery is significant, with an incision into the throat to reach the spine from the front. She already had titanium plates installed into both wrists to alleviate the risk of tendons snapping, after losing use of her right pinkie and being told the remedy would prevent her suffering further reduction of function.

The doctor prepped both of us. He warned us Carol might lose her voice for some time, perhaps even being affected by long-term changes to how she sounded. The recovery period would be at least three to four months, and during her recuperation she would be unable to lie down even to sleep. As it turned out, she was talking the next day—she joked I probably wasn’t as enthusiastic as she was about how much she could say. She lost so much range of motion in her neck, in terms of being able to look around, that it was a full two years before she was approved to drive a car again, though thankfully, ride share services became established in the interim.

The same week Carol returned from the hospital, I finally had a skin biopsy. The dermatologist ordered it after working through Ockham’s Razor, the method of considering simpler causes of a phenomenon before proceeding to more complex possibilities. My lesions persisted, spread, and worsened, becoming an ugly pattern across my chest and my back. I had sores and scabs in my mouth and nose. My scalp was slick with what I thought was pus, but I was informed it was leaking blood plasma. But I was relieved when I finally received word that I had PV.
The onset of my symptoms might not have been happenstance, because Carol’s concerns might have triggered stress. Although PV was latent in my body all along, the doctors explained that anxieties such as a spouse requiring an operation could bring out the manifestations. I was the right age, having just reached the age of fifty when the initial spots showed up.

Our family set up the living room. Our dog even joined us; she had dental work done that week, which for a canine involves anesthesia, and she had multiple teeth taken out—Bebe was woozy on painkillers alongside us. It had seemed like a good idea for Carol to have surgery and Bebe to have dental work, simultaneously. We were in a daze, and we did not postpone the dog’s appointment.

For four months, we stayed in that same space. Carol slept in a fancy recliner we bought specifically for the purpose, allowing her to lean back at just a bit of an angle. We covered the sofa for me, with plastic and layers of sheets, and I had to don a nightcap. We were a sight, Carol in her hard neck brace, me in clothing stained as gruesomely as if a crime had been committed.

I benefited from Carol’s family too. She had arranged for a series of caretakers to visit for a week at a time. She had invited them to help her, but each of them ended up assisting me. The initial regimen my doctors recommended was heavy doses of methotrexate and prednisone. Both have known side effects. I experienced them, severe fatigue from the former and anxiety from the latter; I was drowsy and paranoid. I was useless.

First up was Carol’s grandniece, she was in her early twenties and between jobs. She had to pitch in on every chore and run all the errands. That included doing loads of laundry on my behalf. Even now, she recalls the spectacle of soiled clothing which she had to deal with, which was gruesome but familiar for anyone who has dealt with PV.

The older sister of our health aide was a newly minted pharmacist, as was her husband. My timing was fortuitous. I learned that summer that rituximab was approved for PV. I was interested in trying it but was anxious about the risks I had read about: an adverse reaction that itself could be fatal. Our grandniece and her husband, however, reassured me about its general safety. He was able to offer expertise from his daily task at the hospital, mixing the same infusion I would be receiving.

The truth is, Carol was responsible, not I, for creating a circle of sympathy around us. She was known to neighbors more than me. She is outgoing. Both of us chat with strangers. She is simply better at it.

Over the weeks, we hosted guests who were put to work. We were not instructed to quarantine. But Carol and I confined ourselves. I didn’t want to venture out anyway. I had developed acute sun sensitivity as a bonus condition. Stuck in a limited space, I wondered about my fate if I could not overcome my own body attacking itself relentlessly. Every afternoon, I enjoyed my only respite: I took a bath with Epsom salts, soaking for an hour. I ordered twenty-pound bags. The skin that was not afflicted with PV was wrinkled from being waterlogged.

Our friends each flew in for a week. Carol’s cousin drove up as often as she could. They brought food, cooked food, and kept track of pills we had to take. If it were not for them, we would have struggled. We devised routines. Our friends cleaned the house around us and chatted with us to ensure we were in good spirits and distracted from our ailments. They walked the dog too.

I am not the only one who, in the throes of PV or another malady, ponders priorities in life. If I was not beside Carol, I retreated to the basement to try to work. I only managed to stare at the wall. When you can sit by yourself for extended periods of time, your solitude renders you much less self-centered. You see more clearly the value of company. I cannot imagine how awful it would have been, if I didn’t have anyone. Being a decent person was my new aspiration. No matter how much you would like to perceive of yourself as an individual, or insist you are independent, we are social animals. People who study how we do in these circumstances attest to the advantages of social interaction.

Carol and I could not have anticipated it, but our time together prepared us for the COVID-19 pandemic. We had our own family version of a lockdown. It was more disturbing because all around us people were continuing with normal lives. Yet we were better as a couple for enduring it.

I am grateful to Carol.

Frank Wu is the President of Queens College, The University of New York (CUNY). He is a published author, an avid runner, and theatregoer.
In June 2022, I discovered through a biopsy that I had pemphigus foliaceus (PF). I first recognized that something strange was happening to me in March 2022, when I noticed blisters in my ears. I didn’t think twice about the blisters until they began appearing on my lower back. It was at that time that I decided to go see my primary care physician (PCP).

In April 2022, he had diagnosed me with having eczema and prescribed triamcinolone. With the help of a friend that I was caring for at the time I was able to apply the cream to my back daily after showering. The pain became unbearable until the cream was applied. I returned to my PCP that June and found out I was misdiagnosed. The physician’s assistant (PA) suggested I find a dermatologist.

The first couple of dermatologist offices I called, I was told the only appointments available would be in November and December. I sat at the other end of the telephone in tears and said, “No way, I need to see someone now.” I prayed asking God to please help me find someone who could see me soon. The next call I made; I was able to schedule an appointment for the following week.

I went to see Dr. S., and after examining me he told me I likely had lichen planus. Dr. S. did a biopsy and prescribed clobetasol ointment for the blisters that began appearing on my chest, underarms, and upper back. I returned two weeks later to find out that the results of the biopsy were inconclusive. Dr. S. asked how things were going and I removed my top and said, “You tell me.” The blisters were now on my scalp, face, and neck. My back was full as well as my breasts and stomach.

I first recognized that something strange was happening to me when I noticed blisters in my ears.

Doreen’s Story

Doreen Gonzalez
A shave and punch biopsy were performed, and I was prescribed prednisone. I returned two weeks later to get the results of the biopsies and lab work.

When I returned on June 28, I was informed that I had pemphigus foliaceus (PF). I was prescribed more prednisone and Dr. S. informed me that he hadn’t ever encountered this disease, but he knew someone (Dr. B.) who had and would make an appointment for me.

Upon returning home, I cried and then decided to begin my own research. *What was this autoimmune disease called pemphigus foliaceus and why did I have it?* I looked at Google to read more about it and I did not understand very much, not because I’m illiterate but because I didn’t understand the medical terminology. I then thought about looking at YouTube since it is my “go to” with most things. Lo and behold I found the IPPF website.

I reached out to the IPPF in July 2022 and received an email response with a lot of valuable information. The IPPF Patient Guide was very helpful, providing me with information on PF diagnosis, treatments, nutrition, and side effects from the various medications.

Unfortunately, after my PF diagnosis at the end of June, I didn’t receive a phone call from Dr. B.’s office with an appointment until September. I wasn’t happy that I would have to wait but didn’t have an option. I decided to go to a wellness center for the month of August to see if they could do anything to help me. To my dismay, I came home from the center worse than when I arrived and was admitted to the hospital.

It was painful to wear clothing, so upon applying the ointment to my body I used plastic to keep the areas moist. A nurse visited my home three times per week to help apply the ointment. I could not shower without her being there; it was too painful.

I received my first rituximab infusion in September and the second one in October. The medications CellCept® and prednisone have made life both comfortable and uncomfortable. I feel no pain, but I don’t sleep well. I’ve gained weight, lost my hair, and was diagnosed as diabetic in December. My maintenance infusion was in March. I await the day the marks from the blisters will disappear; I believe it will happen.

I am not certain where I would be regarding education and understanding symptoms and treatments had it not been for the IPPF and the Living with Pemphigus Foliaceus Facebook group.

I felt compelled to share my story because after hearing, reading, and learning about PF from others who shared their stories, I didn’t feel as alone in the world of autoimmune blistering diseases. Some doctors are more knowledgeable than others, and patients have a unique understanding and perspective about what they’re going through.

I am not certain where I would be regarding education and understanding symptoms and treatments had it not been for the IPPF and the Living with Pemphigus Foliaceus Facebook group. I have attended many of the patient education series webinars, as well as informational and educational sessions the IPPF provides. I am truly grateful for the support groups and information shared by the IPPF.

I have a wonderful doctor and I am so blessed that he is knowledgeable about pemphigus. He is over 90 years old and has seen it all. I am a Christian woman, and it is so important for us to share our testimonies with others as we never know who needs to hear what we have to share. It is my hope that my story will help or bring understanding to others who are also going through what I am going through. I also felt it was necessary to become a Healing Hero (pemphigus.org/hero). If my contribution will help someone else or provide more educational training, webinars, conferences, etc., then I want to do what I can to help make that happen.

Doreen Gonzalez is a retired Program Manager of International Mail Security for the United States Postal Service. She was diagnosed with pemphigus foliaceus in 2022. She loves to travel and lives in Richmond, Virginia.
My initial pemphigus vulgaris (PV) symptoms started in my mouth. Oral lesions just stink! Things were bad, and my mouth hurt to move. Every time I ate, I inadvertently opened the scabs on the inside of my mouth and sometimes chewed on them, making the lesion even bigger. A friend I met long after I was diagnosed described that eating things like lettuce and noodles felt like chewing on shards of glass. This was precisely the feeling I experienced but with many other foods, too.

First and foremost, I talked to my doctor and let him know how much pain I was in. There were times when we needed to adjust my dose of medications and others when we added topical medicines like clobetasol or dexamethasone swish. Keeping my doctor informed and in the loop helped me because they understood the impact this disease was having on my ability to be healthy.

I also kept a food journal to see if my mouth hurt while eating certain foods, or if I developed blisters. While there isn’t much research on foods and diet associated with PV, it helped to know my personal triggers. With time, patterns became apparent. I found that sharp objects like tortilla chips would almost instantly cause lesions. Chocolate immediately caused a stinging sensation far more significant than my desire for sweets. Peanut butter also really hurt my mouth, which was a real shame since I ate it almost every day.

I found sucking on ice chips the most soothing as the ice moistened my mouth and provided some numbing.
A registered dietician can help to determine the pH of foods that will make eating less painful and give tips and tricks on how to prepare foods without losing their nutritional value.

But I found other things helpful, too, and I’m happy to share my tips and tricks. I hope some of the things I learned will help you too.

It was hard to eat nutritious foods when all I wanted to do was survive on slushy drinks and ice chips. But I found that a high-quality nutrition shake was easy on my mouth and was a good source of nutrients and proteins. I especially liked them super cold and mixed them up at night to keep in the refrigerator for use in the morning. I also added some ice right before drinking to the blender to make it thick, creamy, and a soft-serve consistency.

Sometimes I mashed or pureed vegetables and food so that they were a soft, baby food consistency. Sometimes I added different broths and combinations of fruits and vegetables for a change in flavors. There were times when I didn’t like how these shakes looked so I decided to make soup. I was able to cook meat and vegetables until they literally fell apart in my mouth, and I could season the soup to my taste so it didn’t sting my mouth. Sometimes I even pureed certain vegetables or added milk and cream to thicken the soups to get textures I could eat without pain. I could also control which vegetables and proteins I added and customize my soup so it didn’t contain any ingredients that hurt my mouth.

Casserole dishes were easier to eat as well since they often had a soft texture. Meats and proteins would fall apart from baking, and the creamy sauces helped soften any vegetables or produce I added to them. Sometimes I added a soft piece of bread or crust depending on my mood and the ingredients I had on hand.

One of the best pieces of advice I received, well after I was in remission, was to seek the guidance of a registered dietician. A dietician is a healthcare professional with training and a license in diet and nutrition. They can help to determine the pH of foods that will make eating less painful and give tips and tricks on how to prepare foods without losing their nutritional value. Most importantly, they can provide ways to eat that don’t hurt your mouth and even help with recipes and meal preparation ideas.

Please discuss any pain you experience while eating with your healthcare providers. I hope sharing my journey will help you to have good discussions with your healthcare team and allow you to eat with less pain.

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.
Founder’s Corner

Finding Support

Janet Segall

The need to have connections and support is strong when living with a rare disease. Around 1996, the first IPPF support group started in New York. At first there would be between five and 20 people who joined in person. Groups then started in Los Angeles, Philadelphia, Sacramento, the Midwest, and Toronto soon after. People told me how helpful attending a support group meeting was for them. For me, meeting others who needed the camaraderie of being around people who knew what I was talking about was enlightening, and I learned new things. Through my own increased knowledge, I was able to continue helping others through the Foundation.

After the IPPF support groups started across the US, I started thinking about people in other countries. I imagined they needed help and support as well, and I asked myself, what could I do for them? In 1998, a woman in England connected with me and let me know that she was interested in starting a support group in the United Kingdom. She wanted the blessing of the IPPF, so I traveled to England and met with Dr. Martin Black, a leading UK bullous disease dermatologist. The first support group in England started, and it leaned more toward advocacy.

Then, in the early 2000s, PEM Friends UK was established and is a very successful group that continues today. With the support of different people and physicians around the world, I was able to attend a new group that was starting in Italy and met with a patient in Paris, who set in motion the group in France (both of which are still going today). Groups became a reality in Germany, the Netherlands, Japan, and Australia as well. We even held an IPPF meeting in London soon after PEM Friends started with people in attendance from around Europe.

Starting in 1998, the IPPF has held an annual Patient Education Conference to connect patients with leading experts in the field of pemphigus and pemphigoid. Typically, the conference is held in person; however, since 2020 and the start of the COVID-19 pandemic the annual conference has been held virtually. It is important for all of us to connect, even virtually, and I encourage everyone to attend this year’s virtual conference (October 27-29). Gaining knowledge about our diseases from each other and the expert physicians that join us, and feeling the emotional support we provide to each other, makes a difference in our journey. Hopefully, we will be able to meet again in person one day. (Our conferences are not only about gaining information and supporting each other, but we also have fun!).
Throughout the years after starting the Foundation and connecting with one another through support group meetings and patient education conferences, I have learned that we all need each other, whether we are in remission or still dealing with an active issue. I’ve been in remission for 20 years without medication and a little activity that comes and goes by itself. I can’t walk away. I’m committed to trying to help whenever and whomever I can. And I am still learning from others as well. We always keep learning. I encourage everyone to pay it forward in our community in whatever way they can. With the number of support groups that exist today, it’s clear to me that we still need each other to help us heal. Check out the IPPF’s event section (pemphigus.org/events) for information about support groups in your area. You can support a new patient by sharing your story: consider writing it for the Quarterly. Consider joining a support group or starting a new one. I know we have helped each other over the years. There are new people being diagnosed with either pemphigus or pemphigoid who need support. So many people have helped each other, even virtually. Be an inspiration and bring support to our community!

For me, meeting others who needed the camaraderie of being around people who knew what I was talking about was enlightening.

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.
THANK YOU TO OUR IPPF HEALING HEROES

Healing Heroes are at the heart of the IPPF community. Their generous monthly gifts allow us to sustain current programs and expand our key areas of operation. If you aren't currently a Healing Hero, please consider becoming one today.

pemphigus.org/hero
Peer Coach Spotlight: Mei Ling Moore

Our new Peer Coach spotlight section features one of our IPPF Peer Coaches, volunteers who have learned how to manage living with pemphigus and pemphigoid. Peer Coaches share their personal tips and tricks, as well as IPPF resources and educational materials that help people affected by pemphigus and pemphigoid to have meaningful discussions with their healthcare teams. Learn more at pemphigus.org/peer-coaches. This issue, we asked Mei Ling Moore to share more about herself.

Mei Ling was diagnosed with pemphigus vulgaris (PV) in 2002. She has been a Peer Coach with the IPPF since 2012. She also organizes the Southern California Support Group. Mei Ling lives in West Los Angeles.

How did you become involved with the IPPF?

I was diagnosed with PV in 2002 and found an email support group that was started by Janet Segall, the Founder of the IPPF. She had organized an in-person support group meeting in Los Angeles at UCLA, and I attended. From that point on, support meetings were held in the Los Angeles area, and I attended all of them.

What is something that you wish you had known when you were newly diagnosed?

There is definitely hope, patients are not alone, there is great support from the IPPF, and you can achieve remission.

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

Attend the annual IPPF Patient Education Conferences. Participate in the EveryLife Foundation for Rare Diseases Rare Disease Week on Capitol Hill events (they are also active on social media). Participate in Rare Disease Day events on February 28. Learn who your senate and congressional representatives are and sign advocacy-related acts that will help the rare disease community.

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

My journey is quite different from most patients. I was given only prednisone and topical medications for ten years. The prednisone has taken a huge toll on my bones. Today, there are many more options for patients with faster results and less side effects.

What are some fun facts you’d like to share about yourself?

Neil Young was my next-door neighbor when he first came to Hollywood from Canada with the Buffalo Springfield. We were in an apartment building in Hollywood that rented for $22.50 per week and it had a Murphy bed that came out of the wall!

I went to the White House three years in a row for an entertainment function and met the Clintons each time!

I spent an afternoon watching a tennis tournament with Tony Bennett. He was there for the World Music Awards and had the afternoon free, so I accompanied him and we sat in Prince Albert’s box. Mr. Bennett also sent me his art book, signed!

There is definitely hope, patients are not alone, there is great support from the IPPF.
Earlier this year, our team worked with the IPPF to send out an email to patients, asking them to fill out a survey. We wanted to understand how support groups affected those with pemphigus or pemphigoid (P/P). Thank you to everyone for their participation in the survey, and we would like to share our results with you.

As many of you know on a personal level, living with an autoimmune bullous disease such as P/P can be very difficult. Previous studies have shown that P/P can decrease quality of life and make it hard to complete normal daily activities. Patients may also experience worse mental health. In our study, we wanted to measure the impact of support groups on quality of life. We included a quality-of-life questionnaire that had been especially developed for people with autoimmune bullous diseases, as well as other validated surveys evaluating the ability to cope and feelings of social support.

We had 378 people participate in our survey. Overall, we found that women, people under 65 years of age, and people with Hispanic ethnicity had a worse quality of life with P/P disease. People who had their disease over three years also had worse quality of life. Our study does not explore why these specific factors are associated with a worse quality of life, but it may be due to existing disparities in healthcare.

Results of the survey exhibit that the IPPF may be making a difference. Specifically, 55% of survey respondents reported having attended an IPPF support group meeting in the last year and 85% of these individuals indicated that support groups help improve their understanding of autoimmune bullous disease. People who attended support groups reported that they did so to increase their knowledge about P/P, meet others with the disease, provide support to others, connect with resources, and to listen to guest speakers. We found that quality of life was improved for those who had attended support groups. People who attended support groups had increased coping mechanisms, especially mechanisms centered on emotion, planning, and humor. After support-group attendance, participants reported less denial of the disease, and less self-blame. Also, support group attendance was associated with increased feelings of family support.

Over the past year, our autoimmune bullous disease clinical research team has had the opportunity to sit in on IPPF-run support groups and hear first-hand what it is like to have these diseases, and to hear the types of questions discussed during these meetings. We take this opportunity seriously to provide the best possible care for patients in our clinic. It is what inspired our team to conduct this research, and why we recommend the IPPF support groups to all our patients with autoimmune bullous disease and their caretakers. You are not alone if you are suffering with your diagnosis. At the support groups, you may discuss many topics including tips and tricks for wound care and treatment options you are considering.
that others may have been through already. Our research shows that support groups run by the IPPF may improve your quality of life and help you cope with the disease.

Our manuscript was published in the *Journal of the American Academy of Dermatology* entitled “Factors associated with impaired quality of life and support group utilization in autoimmune bullous disease.”

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, as well as community engagement and access to care within dermatology.

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

Emanual Maverakis, MD, is a Professor at the University of California, Davis Department of Dermatology. He specializes in the treatment of patients with severe immune-mediated systemic diseases involving the skin.

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**Spotlight**

**Four Questions with Dr. Yoshiyuki Mochida**

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

Dr. Mochida is a Clinical Professor and Principal Investigator at the Boston University Henry M. Goldman School of Dental Medicine.

**How did you become interested in pemphigus and pemphigoid (P/P)?**

As a dentist-scientist, I am interested in researching rare dental/craniofacial diseases. I also direct and teach oral biology, oral immunology, and dental genetics courses using examples of several rare diseases affecting the oral cavity. In 2015, my dental school was approached by the IPPF to integrate patient education woven into the dental school curriculum. At that time, I was initiating a patient seminar series where patients with rare dental diseases were our speakers. As I needed to know which rare disease organization was interested in dental education, I contacted the National Organization for Rare Disorders (NORD) and started collaborating with them. Ms. Mary Dunkle (Vice President of Educational Initiatives) generously helped me with identifying NORD’s member organizations that were interested in dental education. NORD also introduced me to the IPPF, and our mutual need was met. That’s how I started working with and getting more involved with the IPPF.

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

It is important to work closely with your healthcare team, including dentists, to manage your symptoms and prevent complications. It is good to know dentists who have had special training and are consequently more knowledgeable about P/P conditions such as oral surgeons, oral medicine dentists, and oral pathologists.

**What can patients do to better advocate for themselves?**

Communicating clearly with your healthcare team is the first step to better advocate for yourself. Keeping a record and track of your first symptoms will help you communicate effectively with your healthcare team and ensure you will receive appropriate care.

**What is one fun fact about yourself?**

I love taking walks with my golden retriever, Lulu.
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