

The Importance and Value for Physicians and Patients in Engagement with Patient Foundations

By Dr. Brittney Schultz



Becky Strong is a patient with pemphigus vulgaris. For Becky, her journey spanned 17 months, seven physician specialists, multiple encounters with her dentist, and several rounds of incorrect treatments and procedures before correctly being diagnosed with pemphigus vulgaris. She's a registered nurse living in Michigan with her husband Tim and two children. Currently, Becky is the Outreach Director for the International Pemphigus & Pemphigoid Foundation (IPPF), a patient support organization. Becky is responsible for education and awareness related to medical and dental professionals, dental students, and patients at the IPPF. She also spends time advocating at the federal level for patients with rare diseases.

Brittney Schultz is a dermatologist at the University of Minnesota and cares for patients with autoimmune blistering diseases. She has been engaged in the International Pemphigus and Pemphigoid Foundation for several years. While in residency, she previously partnered with the IPPF and her faculty mentor Dr. Nicole Fett to study quality of life in patients with pemphigus. She was a speaker at the IPPF 2018 Annual Patient Conference and nominated for a Star Award for Patient Support. She frequently refers her patients to the IPPF and finds them invaluable in patient advocacy and research.

Becky, tell us about your experiences in joining the International Pemphigus and Pemphigoid Foundation (IPPF).

I joined the IPPF as a patient looking for information and shared experiences with others with pemphigus vulgaris (PV). It was amazing to have the opportunity to talk to somebody else who “just gets it” without explanation. My first annual patient meeting was amazing and I learned so much from the doctors who presented at the meeting as well as real world tips and tricks from other patients.

That meeting was the first time that I had ever met anybody else with PV or a sister disease, pemphigoid, let alone somebody else who could pronounce it. I sincerely thought I would be walking into a movie-like portrayal of World War I field hospitals - with people sitting around in bandages and moaning. Instead, I found a room of vibrant, kind and sincere people who looked like me and had “pemphi-what” too.

More importantly, it was at this patient meeting that I realized what a dynamic organization the IPPF really was. IPPF Annual Patient Education Meetings bring doctors, researchers, scientists, and patients together to learn about current disease treatments, research in the disease space and pipeline medications all at a digestible and easy to understand way with a lot of networking between patients and experts. I realized that my doctor was part of a larger community of physicians who cared for and about patients like me - who were doing research to better understand pemphigus and who also wanted to find better treatments that worked faster. My doctor worked at a major university medical teaching institution that worked with many other doctors and researchers on pemphigus and pemphigoid. Toward the end of the first day of the conference, a doctor said that he was the expert in treating this disease but we, the patients, were the experts in living with these conditions. He went on to say that physicians could learn a lot from their patients about what they experience with this disease. I went home and took those words to heart. I offered to speak to the students and residents that were with my doctors and let them know that I would be willing to share my experience and let them ask questions that they wouldn't normally ask. My oral medicine specialist took me up on this offer and within a few months, I had the opportunity to share my own story at the university's School of Dentistry Grand Rounds.

I asked the IPPF for information on their support services to share with the dental school since my own doctors weren't aware of the IPPF. In exchange, I wrote an article for the Quarterly - the journal of the IPPF. This article would change my life, and I became the first Patient Educator who shared my journey with other dental schools. Eventually, I was asked to become the IPPF Outreach Manager and work full-time to provide support and education to the IPPF community. Currently, I am the Outreach Director.

What benefits have you found as a patient through the IPPF?

When I was newly diagnosed with pemphigus vulgaris, it was truly a game-changer to find a community of people who knew my disease, survived with my disease, and eventually were able to thrive with my disease. Meeting others and learning from their journey helped me move from a victim, past warrior to survivor who had pemphigus vulgaris. The IPPF has so many resources that have helped me:

- IPPF Patient Guide: <https://www.pemphigus.org/wp-content/uploads/Pemphigus-and-Pemphigoid-Patient-Guide-November-2020.pdf>
- IPPF Patient Checklist: <https://pemphigus.org/wp-content/uploads/Patient-Checklist-2017.pdf>
- Patient Education Webinars: <https://www.pemphigus.org/patient-education-webinars/>
- Online discussion group: <https://www.rareconnect.org/en/community/pemphigus-and-pemphigoid>
- Support Group Meetings: <https://www.pemphigus.org/support-groups/>
- Clinical Trial information and more: <https://www.pemphigus.org/clinical-trials/>

As I was able to get my disease under control and eventually find remission, being able to help others by sharing my own journey really gave meaning to all I went through. So often, I asked why this was happening to me? What did I do to bring this on? The reality is that I may never know, but maybe it happened so that I could help others not have to hunt so hard for answers. Perhaps it was to share what I learned about taking care of myself when my skin was literally coming off. Maybe it happened so that I could educate doctors, dentists and students on these diseases so that they can accelerate a diagnosis for others. It has sincerely given me purpose to all I went through and learned knowing that I could help others with pemphigus and pemphigoid.

It's been a true calling to be able to carry on the legacy of IPPF founder, Janet Segall. The IPPF has grown so much from the early days in 1994 to the organization it is today. The IPPF mission now includes four major pillars - patient support, awareness, advocacy and research. Each pillar provides a network of valuable resources that patients, doctors, and researchers can access, use, and easily understand at their own pace.

What benefits have you found as an advocate for patients through the IPPF?

I don't know where to start with this one because there are so many benefits. The IPPF advocates on behalf of all people affected by pemphigus and pemphigoid including with physicians, researchers, the pharmaceutical industry and state and federal government officials. The IPPF shines a light on the patient journey to highlight what patients go through - from a delayed diagnosis, to treatments that take time to work, medication, mental and physical side effects, and more. IPPF also works to inject the patient voice and concerns into clinical trial design to increase patient engagement and likelihood to participation.

Personally, I found a community - instant friends in the beginning of my journey who were there to support me at the lowest point in my life. I will probably always be friends with them because of what we went through together. I've also had the ability to pay it forward. My mission in life has always been to help somebody else with what I've learned, and while this was the darkest period of my life, I feel I've had the opportunity to shine a light so somebody else's journey is easier with the information, tips and tricks that I learned along the way.

It has been an exciting and amazing experience to collaborate with researchers on deepening our understanding of pemphigus and pemphigoid and treatment options, especially in the midst of a pandemic. And I enjoy bringing opportunities to participate in research to our community. There is great power in knowledge and even more in knowing you helped the scientific community with your own journey.

I've also been able to use my own experience and life events within our community in order to advocate for legislative change in Washington D.C. It's inspiring to be able to "Zoom" or walk into the offices of senators, or representatives, and in a short amount of time show how legislation could make a huge difference not only in the lives of the rare disease community, but in the health of every American in this country. It's also an amazing experience to share patient stories with government officials of the Food and Drug Administration (FDA) to show how impactful a pipeline treatment can be and the long-lasting desire for more approved treatments for these diseases.

By advocating on behalf of the IPPF community, I have truly found my life's calling. While this is a labor of love, I know that it takes many stakeholders coming to the table to make a true difference. Patients, doctors, researchers and industry partners all working together day in and day out will ultimately be the way to improve the lives of people with pemphigus and pemphigoid.

Dr. Schultz, tell us about your experiences in joining the International Pemphigus and Pemphigoid Foundation (IPPF).

The IPPF has been a critical factor in my clinical interests and faculty development. I first learned about the IPPF while attending a phenomenal talk at the AAD with Dr. Donna Culton and Becky Strong. Becky shared her experience as a patient newly diagnosed with pemphigus vulgaris and discussed how the IPPF helped her in this challenging time. She also shared how she has then continued to work with the IPPF to help others. It was this talk that inspired me to take care of patients with autoimmune blistering diseases.

Following that talk, I partnered with Becky Strong and Dr. Nicole Fett at Oregon Health & Science University to study quality of life in patients with pemphigus vulgaris. With the help of the IPPF, we sent and received surveys to over 200 patients with pemphigus. I then spent one month rotating with Dr. Donna Culton at the University of North Carolina and attended the 2018 IPPF Annual Patient Conference in Chapel Hill to present on the topic of quality of life in autoimmune blistering diseases. As I transitioned from resident to faculty at the University of Minnesota, I have continued to rely on the IPPF for patient education materials, patient support, practice advancement, and more.

What benefits have you found as a physician through the IPPF?

The IPPF is a fabulous network of physicians and patients. They host regular scientific seminars on various topics for physicians. They are involved in patient research that advances the care for and understanding of patients with autoimmune blistering diseases. During the COVID pandemic, they have provided invaluable resources to help both physicians and patients navigate new and constantly changing information about managing immunosuppressive medications, vaccinations, boosters, etc. They have also helped me advance my career! Through their connections, I have met with many other prominent physicians in the autoimmune blistering world.

How has the IPPF helped you better care for patients with autoimmune blistering diseases?

I refer all my patients to the IPPF. Through their advocacy and support, they allow me to continue helping my patients outside of regularly scheduled clinic visits. I have learned many practical tips from patients such as Becky (see our prior WDS editorial for more of her tips and tricks for living with pemphigus!) that I can then share with other patients. Many patients really appreciate hearing there is someone else like them out there in the world and the IPPF allows them the opportunity to talk to these patients through their Peer Health Coach program. I also appreciate having a reliable source for educational materials that I can confidently provide to my patients.

You have participated in presentations together at the AAD and during IPPF patient webinars. How has that added a unique value to the patient/physician role in engaging with the IPPF?

Through our presentations together, I think it shows further commitment to the patient/physician relationship. It provides mutual credibility and emphasizes that both the importance of both patient and physician perspective.

What resources does the IPPF have for patients?

The IPPF website, <http://www.pemphigus.org>, is full of great information for patients. Most of the resources offered are free to those who use them:

- [Find a Doctor Map](#) - The purpose of this map is to provide patients with contact information for medical and/or dental professionals familiar with P/P. This map is not inclusive by any means. It has been developed from contact with P/P treating physicians, recommendations from patients, and referrals from other physicians.
- [Diagnosis Information](#) - Early diagnosis may permit successful treatment with only low levels of medication. Because they are so rare, pemphigus and pemphigoid are often the last disease considered during diagnosis.
- [Disease Background and Information](#) - Information on the diseases and different subtypes that can be part of the diagnosis.
- [Treatment Options](#) – This page can help patients understand the phases of treatments and some of the common treatments and side effects used to treat pemphigus and pemphigoid.
- [Peer Health Coaches](#) - Peer Health Coaches (PHC) are pemphigus and pemphigoid patients who help more than 1,000 patients and caregivers each year. These specially trained PHCs reduce patient anxiety and uncertainty while providing unbiased disease and treatment knowledge. The goal of our PHC program is to ensure we help every person who needs assistance in the shortest amount of time possible.
- [Patient Education Webinars](#) - The IPPF offers Patient Education Series Webinars featuring leading pemphigus and pemphigoid physicians and scientists. These free webinars are a friendly and casual environment to learn more about specific disease topics.
- Annual Patient Education Conference - During this annual meeting, leading bullous disease experts to present on research and trends, educate about disease management, and answer tough questions regarding the care and treatment of pemphigus and pemphigoid. The 2022 conference will be virtual and details will be announced shortly!
- [Regional and International Support Groups](#) - Support comes from all over. Oftentimes, it is closer than you think. Our website lists groups, associations, and organizations that support pemphigus and pemphigoid patients and caregivers across the United States and around the world.
- [Patient Resource Library](#) - This is a listing of great documents that can provide educational information to be discussed with a patient's healthcare team. This is a great place to find educational resources like the IPPF Patient Guide, Patient Checklist, Wound Care Tipsheet, and more.
- [Natural History Study](#) - Launched in March 2017, the IPPF Natural History Study is a patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US Food and Drug Administration (FDA). This online data system collects, stores, and retrieves patient data for analysis in research studies.
- [Clinical Trial Information](#) - A listing of up to date clinical trial background, information, and research happening in pemphigus and pemphigoid.
- [COVID Information](#) - The IPPF is dedicated to our community during this pandemic. We are working hard to keep abreast of the situation and staying up to date regarding the necessary precautions and recommendations to keep those with pemphigus and pemphigoid safe during this pandemic.

How would a dermatologist best connect their patient with the IPPF?

The easiest way for a dermatologist to connect their patients to the IPPF is simply share our website (www.pemphigus.org) or phone number (916-922-1298) with them and let them know that there are patient resources available to help reinforce the great teaching they are getting in the office. The IPPF also has a flyer (<https://www.pemphigus.org/wp-content/uploads/IPPF-Patient->) that we are willing to share to be included in the post-visit summary. If you feel better connecting patients to a real person, you can also share Becky's email address with your patients: becky@pemphigus.org

How would a dermatologist get involved with the IPPF?

There are many ways for dermatologists to get involved with the IPPF and we are excited to have you!

- [Join the Find a Doctor Map](#) - We are always looking to expand our network of knowledgeable providers worldwide.
- [Join our email list](#) - Scroll down on our main page to join our email list to keep up to date on the latest news and events in our community.
- [IPPF Scientific Series](#) - In close cooperation with Drs. Ralf Ludwig & Katja Bieber of the Lübeck Institute for Experimental Dermatology at the University of Lübeck, the IPPF Scientific Seminar Series is a scientific educational program with experts from various international institutions who present on their scientific findings on pemphigus and pemphigoid. Content will highlight recently published and/or unpublished data in both basic and translational research.
- [Patient Education Series](#) - As described above, this series is geared towards a patient's understanding, but many doctors and industry professionals attend these webinars to take a deeper dive into the topics presented.
- Become a [Medical Advisory Council](#) Member - The IPPF has medical and dental professionals who provide guidance on many aspects of the foundation's activities such as patient education and support and clinical trial updates.
- Join the IPPF [Board of Directors](#) - Become a member of the governing body of a nonprofit. The members of a nonprofit board focus on the high-level, oversight, and accountability of the organization.
- We are always looking for contributors to both the [Quarterly](#) and [PemPress](#). Email editor@pemphigus.org to get in touch.
- [Volunteer](#) - The IPPF is looking for people who can help with specific jobs or have certain skills that have significant benefit to our community.
- [Become an advocate](#) - Together, we can drive favorable policies by reaching out to legislators and decision-makers to inform them of our public policy concerns, bring attention to the disease and inform the public about P/P. The IPPF advocates with the American Academy of Dermatology Association and Rare Disease Legislative Advocates annually.
- [Become a Healing Hero](#) - Healing Heroes go above and beyond to support the IPPF community by making sustaining, monthly gifts to support our mission of improving the quality of life for all those affected by pemphigus and pemphigoid
- We are open to other ways for you to be involved. Please feel free to contact us to discuss your ideas! info@pemphigus.org