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Journal of the International Pemphigus & Pemphigoid Foundation

**Put It On Your RADAR:
P/P Awareness**

SPRING 2017 • ISSUE #88

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Pemphigus &
Pemphigoid
AWARENESS

Put it on your **RADAR**

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Message from the Executive Director



I can't believe it has been almost a year since being asked to step in as Interim Executive Director of the IPPF. I am happy to announce that this position is no longer temporary, and I am now the permanent Executive Director.

It has been an honor and privilege to work with a group of individuals who are so dedicated and driven to help all people affected by pemphigus and pemphigoid. It continues to amaze me how much we have accomplished in less than a year, and in this edition we will share just a few of those achievements.

Recognizing the need to reduce diagnostic delays, we have taken the idea of an awareness campaign and transformed it into a permanent program within the IPPF to provide education to dental professionals, students, and faculty. The IPPF is spreading awareness across the country in congressional offices, doctors' offices, newspapers, online, and from person-to-person by sharing our stories. We are banding together in support groups and meeting with researchers and scientists, learning how we can improve our quality of life through support and better therapies. Thanks to your continued support and efforts, we are letting others know that no disease is too rare for a cure!

The IPPF is committed supporting P/P patients, but we need your help to move things forward. Together we can create even more awareness to advance our cause. We urge you join the new IPPF Natural History Study, listen to our Patient Education Series, or attend the 20th Annual Patient Conference in Newport Beach, CA. Get involved by volunteering at an exhibit booth, joining a support group, or writing your congressional representatives.

Thanks to you, the foundation's reach continues to expand! We will remain focused on advocacy, awareness, community, and research to find a cure for pemphigus and pemphigoid.

Gratefully,



Marc Yale
IPPF Executive Director

marc@pemphigus.org

Pemphigus & Pemphigoid

AWARENESS

Put it on your RADAR

Awareness Campaign Becomes a Program

Kate E. Frantz

It started with a vision to make more people aware of pemphigus and pemphigoid (P/P). Those following the IPPF Awareness Campaign may know it was designed as a three-year initiative with January 2017 as a tentative end date. Well, January has come and gone, and the Awareness Campaign—or should I say, Program—is here to stay.

While “campaign” implies a temporary project, “program” suggests a permanent solution to a problem. We have made significant progress in the dental community, reaching over 10,000 dental professionals and students in person. However, it is clear our services are still needed to promote education and awareness of P/P. We will continue our efforts to reduce patient diagnostic delays by presenting to dental students and practitioners, exhibiting at conferences, publishing articles, and much more.

Let me take you on a journey over the past three years,

highlighting the Awareness Program’s achievements in “putting P/P on the radar” of dental professionals.

Dental School Presentations

P/P patients share their emotional diagnosis journeys with dental students across the country. To date, Patient Educators have provided 38 presentations at 15 dental schools reaching approximately 4,000 students and faculty. Check out our Patient Educators in action at <http://pemphig.us/pe-highlights>.

In-Person Continuing Education (CE)

Both patient and scientific speakers present CE courses on P/P to dental practitioners. Speakers often present together, providing a unique experience where the audience learns scientific information along with a patient story. The IPPF has presented 10 CE courses, reaching over 600 dental professionals.



IPPF Awareness Program Manager Kate Frantz with Marcy Syms and Mindy Unger at the Greater New York Dental Meeting.

Dental Conference Exhibits

The IPPF rents exhibit space at dental conferences across the United States. Staff and volunteers share their diagnosis stories, distribute educational materials, and answer questions about P/P and the foundation. Since November 2015, we have exhibited at 10 dental conferences, reaching over 5,600 dental professionals at these events.

Publication of Articles in Dental Magazines, Journals, and Websites

The IPPF seeks opportunities to publish articles on P/P to increase our messages' reach. Thirty dental societies in eight states have accepted an IPPF article on P/P for publication in their various newsletters and social media outlets. Most notably, the IPPF and Indiana University School of Dentistry's manuscript entitled "The Patient Educator Presentation in Dental Education: Reinforcing the Importance of Learning About Rare Conditions" was published in the *Journal of Dental Education* in May 2016.

Online and Print Educational Resources

Have you been to the Awareness Program's website, PutItOnYourRadar.org? This site is designed specifically for dental professionals. We have a resource page, videos, and materials available for print. Make sure to tell your dentist to visit our site!

News Updates

Generating fresh online content makes it easier for patients and physicians to find us. One way we do this is through PemPress, the IPPF news site, www.pempress.com. PemPress dedicates an entire section to the Awareness Program.

E-Blasts to Dental Community

The IPPF remains in contact with dental students and professionals by sending periodic emails to the dental community. Whether to inform them of our participation at an upcoming exhibit, thank them for stopping by our booth, or sending general resources, this serves as an additional communication method.

Volunteers

Patients, friends, and family have generously contributed their time to the Program by exhibiting at dental conferences, presenting to dental societies and schools, and sharing information with their local dentists. Are you interested in getting involved? Email ambassadors@pemphigus.org to learn more or suggest your ideas.

Evaluation & Data Collection

The Awareness Program is all about data! We conduct surveys with students after each Patient Educator presentation. Over 90 percent of students report the



IPPF Patient Educator Hannah Heinzig at a recent presentation at the University of Missouri - Kansas City School of Dentistry

Patient Educator presentation will change their future clinical decision-making and help them to remember important information about P/P. Here are a few quotes from students:

"Thank you so much for sharing your private experience with us. This was the most valuable and probably the one thing I will retain from this class."

"I really enjoyed this presentation and I strongly believe that it should be given to as many dental students as possible."

"The presenter was excellent! Her presentation really is helping me to remember much more about pemphigus, compared to what I would remember based on our dental school lectures alone."

We also survey dental professionals while exhibiting at conferences. Preliminary results reveal that 40

percent of dentists and 50 percent of dental hygienists report low confidence levels in their ability to recognize the clinical presentation of P/P. Clearly, we are still needed!

The Awareness Program could not do what we do without the generous financial support of the Sy Syms Foundation and the Unger Family. Thank you!

We also extend our gratitude to the IPPF Awareness Program Committee, Dental Advisory Council, and Content & Curriculum Committee for their support.

The IPPF's next quarterly fundraiser will specifically support the Awareness Program. Keep a lookout for a letter in the mail with instructions on how to donate. Or, as always, contact awareness@pemphigus.org or visit pemphigus.org

Kate Frantz is the IPPF Awareness Program Manager. She lives in Arlington, VA, with her husband.

Thank you to the
SY SYMS FOUNDATION
and the
UNGER FAMILY
for their continued support
of the IPPF Awareness Program



Awareness at Boston University

Rebecca Oling

It wasn't easy getting to this meeting. After a four-hour train ride, I decided to walk to my hotel, nearly two miles away. It was rush hour, days after a major snowstorm. Boston was cold, and the streets were crowded with traffic barely visible beyond mounds of blackened snow.

The walk was neither refreshing nor picturesque; it ended with a gauntlet of addicts outside the methadone clinic near my hotel. No sooner did I arrive in my hotel room when the phone rang. He was early, and I was spent. Everyone has a story.

There is a saying that one should never be too busy to meet someone new. Most of us are so harried that we forget to hold a door, to let someone hop a grocery line, to stop for someone who seems lost. Or, these days, to even look up. Last month, during that post-snow Boston trip, I took a chance to set up a meeting with Cataldo Leone, DMD, the Dean for Academic Affairs and Professor of Periodontology

and Molecular and Cell Biology at Boston University (BU).

It was immediately apparent that Dr. Leone was the type of person who takes the time to be kind. He was thoughtful and could not have been more accommodating, offering to pick me up directly at my hotel. From there, we headed to a favorite restaurant where he had much-needed business to conduct: confirming arrangements for his mother Carmella's birthday brunch the following Sunday.

Dr. Leone was a catch of an interview, not only because he is such a busy person, but also because he has taken some of what the IPPF has provided in patient educator presentations and molded it to his

needs at BU. As part of the IPPF Awareness Program, patient educators visit dental schools and talk to students in oral pathology courses about their diagnosis journeys. These presentations are paired with clinical disease information. The aim is to ensure that students recall what they have learned and understand the importance of early diagnosis from both a clinical and emotional perspective. But that isn't quite how the story went at BU for the IPPF.

The IPPF has presented at BU twice in as many years. We have long asked for these experiences to be part of the curriculum, as a kind of requirement. Dr. Leone has felt that making it a requirement risks students coming with ulterior motives—namely, to get the credit. This past year, Dr. Leone acted on a visceral understanding that offering these “lunchtime learning opportunities” was memorable and effective enough to warrant seeking out patients with other rare ailments. Students do show up—sometimes

out of hunger and looking for free pizza—often with an intense curiosity at the opportunity to meet someone with a rare disease they might someday see in practice.

With this approach, Dr. Leone has created a kind of community of practice. It was not what we expected when the IPPF began the Patient Educator Program, but that's the beauty of what Boston has done. Rather than turning away from the opportunity altogether, Dr. Leone worked closely with Kate Frantz, IPPF Awareness Program Manager, to ensure that BU's participation aligned with the program's guidelines. The IPPF's Awareness Program can typically pay for the speakers' travel and expenses if the school can meet an attendance requirement of 100 people. Because BU so valued the program, they offered to sponsor the IPPF's visit. With approximately 80 students routinely attending the lunchtime presentations, it is clear from comments that students are actively learning lessons they will remember for years to come.

investment. Students take the time to show up. His eyes gleam as he admits he'd like to do more actual assessment of these programs. He's also quick to point out that assessment is a tool to measure impact and that you can already feel that the "ball is rolling." The patient educator approach is impactful precisely because it's personal "when you interact with people. As people to people it is always better than one dimensional."

Part of the multidimensional success of the BU School of Dental Medicine enrichment opportunities must be credited to Dr. Yoshiyuki Mochida. When he began to work at BU in 2009, Dr. Mochida's interests were in rare diseases affecting craniofacial tissues. Mostly, he had been working on Dentinogenesis Imperfecta (a rare, inherited disorder in which the teeth are discolored, often translucent, and break easily). He was contacted by the boyfriend of a woman with the disease who must have seen his name associated with the research on the subject. The woman's daugh-

and this led him from research to action. In that same year, the IPPF sent Becky Strong to BU as a patient educator, and the pair met.

"It struck me that this could be a series," Dr. Mochida said. It could only benefit dental students to understand these complex awareness and advocacy issues as they embark on their professional careers. Perhaps P/P, like Dentinogenesis Imperfecta, are inherited, impacting the patient's concerns about having a child. Maybe pemphigus and pemphigoid are not daily encounters in clinical practice, but clinicians will see these or similar diseases—with all their symptoms and accompanying complications. Dr. Mochida felt it was imperative to make this clear to his students. "I was already sparked on the rare disease path and the patient needs," he explained, "but students might not be thinking about all those factors that affect a patient's ultimate success."

Dr. Mochida approached Dr. Leone with the idea about an enrichment series. He then contacted the National Organization for Rare Disorders (NORD) to find more patient speakers. NORD referred Dr. Mochida to the IPPF. Though clinicians have often used actual patients as models of one issue or another, the idea of partnering with patients as educators—true experts in their own experiences and diagnostic pathways—is an exciting and new development. According to Mary Dunkle, Vice President for Educational Initiatives at NORD, the IPPF's program is an "excellent service" that is "absolutely innovative."

In fact, NORD began to see the

Awareness is situational. It is about context. It is about the scene and the story.

"We know each school is unique," Frantz said. "Ultimately, what is most important is raising awareness of pemphigus and pemphigoid. Boston University is a terrific example of a school with a unique vision that is willing to work with us to make that vision a reality."

About 10 to 15 percent of the BU School of Dental Medicine student body chooses this enrichment without enticements, according to Dr. Leone, further justifying the

ter also suffered with the same disease. Dr. Mochida helped by setting them up as patients in BU's clinic. In 2015, a second family contacted him. This time, it was to get help advocating with an insurance company (Dentinogenesis Imperfecta is not covered in Massachusetts because it is considered a congenital dental issue. It is only covered in *one* state—New York). The problems patients faced became Dr. Mochida's problems,

value of such a service three years ago when it sent a contingent of patients to the annual American Medical Student Association conference. Dunkle was hooked. “I was struck by the number of students who told us there, or who wrote to me afterwards, that they would ‘remember this for the rest of my life.’” It’s an effective way to train the whole clinician: remind them that patients are people, each with a unique disease story.

For the IPPF, partners like NORD can help to get patient stories across to a wider audience, while also paving the way for other patients to share their experiences. Though NORD’s program is newer than the IPPF’s, the “demand is there,” Dunkle affirms. “We often get requests for various community events—not necessarily in the classroom.” This is an important distinction from the IPPF’s focus on curricular ties. However it happens, the stories “go with these students the rest of their lives.”

There are myriad ways of communicating patient stories, especially when shared opportunities make sense for an organization and its patients. As a patient and former board director, what matters most to me is that there are passionate people who aren’t afraid to tell their stories with a clear goal in mind, even if it doesn’t begin the way we envisioned. Awareness is situational. It is about context. It is about the scene and the story. And while we can never be “too busy to meet someone new,” we should also never be so myopic as to ignore the opportunities that life presents when our stories come together. What is your story? How might being open to it, learning to tell it, and understanding how it intersects with others change the status quo?

Rebecca Oling, MLS, is a librarian with a background in Education at SUNY Purchase College. She is the author of several articles on instruction in libraries and more recently has begun to publish on instructional issues in the rare disease world.

The Impact On Dental Students

Timothy J. Treat, DDS

At the 2017 American Dental Education Association (ADEA) Annual Session in Long Beach, CA, I reconnected with the person responsible for one of the most impactful learning opportunities of my entire dental school experience. Becky Strong, an IPPF Patient Educator, presented to my second-year DDS Oral Pathology class at Indiana University School of Dentistry in Spring 2014. She captivated over 100 of us with the details of her long journey to obtain a diagnosis of pemphigus vulgaris. Her presentation was exceptional, and I highly recommend that all dental students have the opportunity to learn from an IPPF Patient Educator.

The opportunity to supplement formal or scholarly material about pemphigus and pemphigoid with the personal story of a live, in-person patient was a very memorable experience that put a face to the disease. During her presentation, Becky showed clinical photographs of her own mouth in various stages of the pemphigus vulgaris disease process. She described the painful lesions and how they made her feel as she visited various health-care providers searching for an answer. Most alarming to the students in the room, she described the inaction of her general dentist, which directly led to many additional months of pain and suffering before she ultimately arrived at a diagnosis.

It is critically important to provide dental students with a variety of learning experiences and to remind us that behind every disease we study are real patients with those diseases. As a result of this one Patient Educator experience, I am far more likely to recognize the signs and symptoms of pemphigus and pemphigoid in my practice of general dentistry and, more importantly, act on that recognition without hesitation.

Reconnecting with Becky in Long Beach reminded me of the impact one person can have on a captive audience at the right time in their training. I spent a brief amount of time at the IPPF booth in the exhibition hall sharing my experience with other educators and students, one of whom had seen Becky’s presentation at NYU and felt a similar impact. I strongly encourage every dental school to consider inviting an IPPF Patient Educator into their classrooms.

Tim Treat is a general practice dental resident at the Roudebush VA Medical Center in Indianapolis, IN. He currently serves on the ADEA Board of Directors. Following his residency, he will join the faculty at Indiana University School of Dentistry as a postdoctoral clinical teaching fellow in the Comprehensive Care Department.

Courses for Dental Professionals

Paul C. Edwards, MSc, DDS, FRCD(C)



Over the past two years, the IPPF's Early Diagnosis Awareness Program has provided in-person continuing education (CE) courses that reinforce how to recognize and diagnose pemphigus and pemphigoid (P/P) to over 600 dentists, dental hygienists, and other allied health care providers throughout the United States. This series of CE programs plays a central role in supporting the IPPF's mission of "improving the quality of life for all people affected by pemphigus and pemphigoid through early diagnosis and support," especially in light of the fact that the majority of patients with pemphigus vulgaris and mucous membrane pemphigoid experience oral lesions as an initial symptom.

As part of their pre-doctoral dental curriculum, dentists and dental hygienists are trained in recognizing, diagnosing, and treating many conditions that can present in the head and neck area, including P/P. These many conditions, numbering in the thousands, are covered extensively in oral and maxillofacial pathology courses. Nevertheless, dental providers face several challenges in making an early diagnosis of P/P.

For one, numerous other conditions, many of which are more common than P/P, may overlap in clinical presentation with P/P, especially early in the disease process. Secondly, they are rare, with estimated prevalences of 1:30,000 to 1:1,000,000 for pemphigoid and pemphigus respectively. As a result, the average general dentist may practice for years before encountering a patient with P/P. Therefore, it is understandable why the dental practitioner may not consider P/P in their initial assessment—especially for patients presenting early disease symptoms. As a result, many patients with P/P go undiagnosed for months. However, since early treatment of both P/P is associated with improved outcomes, decreased overall disease severity, and increased rates of remission, the importance of a prompt diagnosis cannot be overlooked.

The key to early diagnosis of P/P is relatively simple: practitioners must routinely perform an incisional biopsy for patients presenting with undiagnosed chronic oral erosions or ulcers. As with other conditions, diagnosis precedes treatment.

The IPPF's continuing education courses aim to

remind dental providers of the importance of considering P/P in the differential diagnosis of patients with persistent red or ulcerated lesions of the mouth.

During these CE courses, the pathogenesis of both pemphigus and pemphigoid are initially reviewed (autoantibodies against different protein structures responsible for maintaining the attachment of the epithelium to the underlying connective tissue or between the layers of the epithelial itself). Clinical information is complimented by an IPPF patient educator's

personal story. This moving account of the long and frustrating path to diagnosis concludes with an appeal to consider P/P in the diagnosis of patients with chronic oral lesions. Returning to the scientific portion of the presentation, several areas are emphasized: that other, more common, immune-mediated lesions—including erosive lichen planus and lupus erythematosus—can lead to ulceration or erosions that overlap in clinical presentation with P/P; the critical importance of performing a biopsy to make a definitive diagnosis; and the reality that many patients with P/P do not initially present with the widespread tissue peeling that is highlighted in most oral pathology textbooks. The all too common early misdiagnosis of P/P lesions as representing an allergic response to medication or oral care products is also highlighted. Approaches to performing biopsies, types of biopsies, and overall management of P/P are further reviewed. Finally, dental management of P/P patients is emphasized.

Audience feedback has been extremely positive, particularly with respect to the personal accounts provided by IPPF patient educators Becky and Hannah. Many lecture participants have commented that the moving description of the patient presenters' long path to diagnosis, the impact of this delay on their personal and family lives, the sense of relief they experienced

The key to early diagnosis of P/P is relatively simple: practitioners must routinely perform an incisional biopsy for patients presenting with undiagnosed chronic oral erosions or ulcers.

on finally having a diagnosis, their subsequent bewilderment in realizing they could have been diagnosed months earlier by means of a routine incisional biopsy, and the challenges they have since faced in treating their disease will help them to remember the importance of considering P/P in their patients. This positive feedback from lecture attendees confirms the impact of these presentations and how this series of continuing dental education courses on P/P supports one of the principal objectives of the IPPF: to remind dental health care providers of the importance of putting pemphigus and pemphigoid “on their radar.”

Dr. Edwards is Professor in the Dept. of Oral Pathology, Medicine and Radiology, Indiana University School of Dentistry. He is a member of the IPPF Awareness Program's Dental Advisory Council, Awareness Program Committee, and Content & Curriculum Committee.



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Exhibit Booths & Boston's *Blister Sisters*



ANOTHER SUCCESSFUL YEAR AT YANKEE DENTAL CONGRESS

Ellen Levine

For the second consecutive year, the IPPF, with members of the Boston Support Group, participated in the Yankee Dental Congress (YDC) this past January. YDC is New England's largest meeting for professionals seeking dental continuing education, as well as dental products, services, and resources. With nearly 27,000 dental professionals in attendance from across the US, YDC is the fifth largest dental meeting in the country.

The IPPF's participation at YDC offered a strategic opportunity to educate thousands of dental professionals about our rare diseases.

I remember when the IPPF first launched the Awareness Campaign by targeting the dental community. I couldn't think of a more appropriate and thoughtfully designed program, as I reflected on my own experience and initial struggle with pemphigus, seeing dentist after periodontist; oral pathologist after oral surgeon; physician after specialist; in my search for a diagnosis and treatment plan.

It was my sincere privilege to work alongside my

fellow "blister sisters" and Awareness Ambassadors from Boston: Sam (Cheryl) Iwamoto, Deb Teperman, and Aimee Reveno, as well as IPPF Outreach Manager Becky Strong. As patients, we were perfectly positioned to engage attending dental professionals with our first-hand accounts of living with these blistering diseases.

The IPPF booth at YDC was situated among other nonprofit organizations in the education aisle, which set us apart from vendors selling dental products and services. As conference attendees streamed by our booth, we shared our stories from diagnosis to treatment, answered questions about P/P, and provided information on the IPPF. I found it most encouraging to chat with students—dental students, as well as students studying to be hygienists and assistants—the future generation of dental professionals, who were eager to learn about these disorders. Several individuals were so moved by our personal stories that they requested to have a patient present at their respective schools and organizations.

As Awareness Ambassadors at YDC, not only did we

contribute to the larger goal of spreading awareness of our diseases, but we also gained an intangible satisfaction in return. Deb Teperman sums it up with the following:

“This year was my second time volunteering in Boston. I never imagined finding good things about having this disease, but representing the IPPF at the YDC comes pretty close. I loved meeting up with familiar volunteer faces whom I now call my friends.

“As rare disease patients, I think we sometimes feel like we live in one big, unlucky disease ‘bubble’ and that we are at the mercy of limited treatment options and professionals who know less about our disease than we ourselves do. I am heartened by the enthusiasm and energy of the next generation of medical professionals who stopped by our booth to ask questions.”

Sam Iwamoto describes her YDC experience as follows:

“IPPF has been a lifesaver for me. Right from the beginning of my disease, the IPPF provided me with solid information as I stumbled around trying to absorb everything. The IPPF was my safe place to access knowledge and to get help. In turn, the IPPF also rewarded me with supportive friendships. I was excited to give back in a meaningful way by volunteering with the IPPF at YDC.”

Those who were most attentive to our message at YDC were the dental support staff: hygienists, dental assistants, office staff, as well as the dental students. These are important groups as they interact with dental patients the most and are in a position to identify these diseases at the early stages. Also, they were made aware of the IPPF and the support the organization can provide to dentists, staff, teachers, as well as to other lost patients like I once was.

And from Aimee Reveno:

“The folks who I chatted with had a variety of stories, from suspicion of a patient in denial for decades, to folks who had never heard of the disease. Gratifying conversations included those with clinicians who might now be closer to making a diagnosis for their patient with intermittent or confusing symptoms. All the people who we spoke with responded to the fact that we, ourselves, were patients. They were moved that we had

‘reached the other side’ after an awful diagnosis and a scary, uncertain road. They were grateful for our presence and promised to keep us, and the IPPF in mind, in the unfortunate event one of their patients needed us.”

By participating in these dental conferences . . . the IPPF is making a significant impact in shortening diagnosis times for future P/P patients and helping them return to normal lives.

Despite these wretched diseases, as IPPF Awareness Ambassadors we have found a wonderful community that understands the pain and suffering we’ve each endured, but also supports and uplifts one another. There is power in giving back to our community.

Thank you to the IPPF for working to improve the quality of our lives. By participating in these dental conferences, and by soliciting the contribution of volunteer Awareness Ambassadors, the IPPF is making a significant impact in shortening diagnosis times for future P/P patients and helping them return to normal lives. I look forward to the IPPF’s continued participation in YDC in what has become our annual New England tradition here in Boston.



Ellen Levine, Sam Iwamoto, and Deb Teperman at YDC.

Ellen Levine is a PV patient from Boston. She works for the Armenise-Harvard Foundation, a foundation at Harvard Medical School (HMS) that supports leading scientists at HMS and at institutions in Italy in the pursuit of scientific discovery in the field of medicine.

Awareness & Storytelling

Becky Strong

If you are reading this article, there is a good chance your life has been affected by pemphigus or pemphigoid. Perhaps you were diagnosed with one of these diseases. Or maybe you've supported a loved one as they suffered through the worst of their symptoms. No matter your perspective, you have a story to tell.

Some are short stories due to a quick diagnosis and excellent response to treatment. Others need the space of an epic novel to adequately contain the journey from initial symptom to remission. Many of us are still writing our stories about our encounters with these diseases.

We all contain the makings of a good book. We just need to open ourselves up and be ready to write. Our stories are real. They are firsthand experiences of what disease and treatment can do, and our loved ones are a living testament to the collateral damage disease can

cause. Even if it's been a while since we've been in the trenches, our story is still worth sharing.

Our stories are emotional.

Stories require an emotional element to make them real. Our stories have pain, both physical and psychological. Our lives have humor, joy, despair—sometimes all at the same time. These emotions make our tales ring true. Our stories are not a list of objective findings. They are me. They are you. They are us.

Our stories are easy to understand.

There aren't any thick plot twists. A patient suffers from an unnamed illness; that illness is relentless; the patient strives to find a cause and treatment. It is the simplicity of the story that aids in memorability because it's easy to understand.

Our stories are impactful.

Regardless of the size of the audience, our stories can be validated by listeners or readers. We do not worry about how many people will hear our stories, but rather if they will be heard. We know that sharing our stories with the right person may be the one thing that helps somebody else on the same journey.

Our stories have value.

Doctors may be the experts in treating our diseases, but we are the experts in living with them. We can teach our area of expertise like no professor could ever do.

Julia Campbell, Principal of J. Campbell Social Marketing, says that “to be storytellers, it is important that we are a true believer in the cause. We must know that by sharing our story, we evoke change.” We must be passionate. She says that preparation is key in delivering a great story. We must present our stories in a logical manner so our audiences can understand the messages we hope to convey.

We also need to understand our listeners. We need to understand what they care about and carefully craft our story to meet their needs. Julia Campbell goes on to say that it’s important to be relatable. We want listeners to identify with us. This is what makes it real to them.

So . . . how do we do this? It can feel overwhelming, whether you are writing a letter, having an intimate conversation, or standing before hundreds of people. I’ve been there; it’s not easy. But I promise, you know this story. You lived through every moment and came out a survivor.

To get the message out there, we need to be proactive and approach others to see if they are willing to listen. A.A. Milne says in *Winnie-the-Pooh*, “You can’t stay in your corner of the Forest waiting for others to come to you. You have to go to them sometimes.”

To help organize your thoughts, I’ve put together a list of ideas that helped me begin to tell my story. Just like finding our diagnosis and starting treatment, I found it easier to break things down into attainable steps. Every journey starts with the first step, and that first step is usually the hardest.

These are the steps I use in telling my story:

1. Commit to making the effort. Your story will only be as good as the effort you extend. You survived

this disease, found a diagnosis, and started treatment. That is harder than telling your story will ever be.

2. Choose your method. Not everybody is cut out for public speaking. You may be more comfortable writing your story or sharing it with a friend. You may even decide to share it with a group of friends or a book club.

3. Determine who the listener is and how you will customize your message. It’s all about the audience. What message do you want to convey? It may not be possible to say things to medical professionals that we say to our friends. We need to make sure the listener is comfortable with what we are telling them. Think about the setting where the story will be told. Will it happen at dinner with friends, a congressional office, a university? Molding our story to fit the context is a huge part of being successful.

4. Come up with a logical outline so the story makes sense. I find a timeline works best for me. It provides a logical, structured, step-by-step progression of what happened in my life.

5. Include emotions. The good times and bad times—the funny and the sad—are equally important. It’s hard to feel the depth of the pain you went through if you don’t provide contrast. Emotions humanize our stories. Also, don’t forget to include the ups and downs of caregivers. They are often victims of our diseases, too.

6. Practice, practice, practice. Being prepared to tell your story is just as important as what you say. Storytellers need to be able to improvise and not be too rigid in their delivery. Try to make it more like a conversation.

7. Be enthusiastic. Let your audience feel your passion. Help them to “walk in your shoes.”

I hope you will take the time to tell your story. Please know you can contact me if you would ever like assistance. And don’t forget to share the experience with the IPPF, as we love to hear firsthand accounts of awareness being raised within our community.

Your voice is important. Your voice is strong. This is your story to tell.

Becky Strong is a PV patient and the IPPF Outreach Manager. She was diagnosed in 2010, but is currently in remission. She lives in Michigan with her husband Tim and her young family.



Last Year's

Rent

Tina Santomauro

Since the beginning of July 2016, I've been using children's toothpaste to brush my teeth. I prefer Colgate's line for "growing adult teeth," not having baby teeth and all. Sadly, the tube isn't covered with Minions, Barbie, or Super Mario. (Yes, they make Super Mario toothpaste.) My bubble blast mouthwash, however, does bear the likeness of Elsa from *Frozen*, so living with mucus membrane pemphigoid hasn't been a total loss. But getting diagnosed? That was.

My mouth first began to show signs of the disease at the end of June 2016. I was out to dinner with a friend, eating the same fish tacos I always ordered, but this time its mild salsa burned my taste buds so much that my eyes started to tear. My friend and I assumed a rogue jalapeño had found its way into my meal.

A handful of days later, my mouth started to burn whenever I brushed my teeth (with adult, mint-flavored toothpaste). And let me tell you, there's nothing quite like standing alone in your bathroom, brushing your teeth, with tears streaming down your cheeks. (Note to self: apply mascara *after* brushing.)

By July, I had white patches and blister-like lesions all over my mouth and tongue. There were no rogue jalapeños anywhere; it was just a blistering, snowy mess.

The first thing I did was go to urgent care. There was one in my neighborhood; it seemed like the logical choice. Once there, I was diagnosed with "hairy leukoplakia." Google that for a second, I'll wait right here.

As you may have guessed, after my diagnosis the doctor questioned if I could have AIDS. According to

him, only people living with HIV/AIDS develop hairy leukoplakia, and it is the first sign someone HIV positive will see when their HIV is turning into AIDS. He then gave me a rapid response HIV test and, even with its negative outcome, told me I needed to get a lab test.

This couldn't be real. What would I tell my mother? Could I just go back to crying while brushing in the bathroom?

The urgent care doctor then prescribed me a medical mouth rinse to help tame my victimized mouth. It was to be ready in ten minutes at the neighboring CVS, so I made my way out of the urgent care facility and onto the busy Brooklyn street. I stood in the middle of the sidewalk—probably in the way of every passerby and certainly under a sweltering sun—filled with confusion and fear. Then I did it: I

Googled hairy leukoplakia. The doctor wasn't kidding. "If I have hairy leukoplakia," I thought, "I must have AIDS."

It couldn't be. And if it was—oh, to think of how careless I could have been all these years if I was just going to end up here!

... both followed up that diagnosis with a blank stare and one question: "How on earth did you get this?"

On the flip side, inside this ridiculous and immature exterior is a more laid back, rational 40-year old lady. And that part of me thought: I don't even date that much. I couldn't possibly have HIV . . . much less be on the verge of AIDS. With the theme song to *Rent* in my head, off I went to collect my prescription at the local CVS.

To my surprise (not really) the medication urgent care prescribed didn't work, and my mouth continued to get worse. My esophagus began to burn whenever I swallowed anything, even water.

Maybe they were right. I had HIV and it was turning into full-blown AIDS right before my eyes—and mouth—and there wasn't a thing I could do about it! Except get a second opinion.

A week later, I saw a dentist, and a week after that, a general practitioner. Both appointments were eerily similar. Upon one tiny glance inside my mystery mouth, both medical professionals diagnosed my condition as "oral thrush," and both followed up that diagnosis up

with a blank stare and one question: "How on earth did you get this?" (Little did I know that was only the first of dozens of times I would be asked that same question by many a doctor.)

The general practitioner also gave me a rapid response HIV test.

Negative again. I walked away from both appointments after being told to continue taking the medication urgent care had given me. "It should start working . . ."

The following Sunday, instead of eating dinner

with my family at 2:00 p.m. (hey, we're Italian) my mom took me to the ER. The doctor there was also quick to decide I had oral thrush and prescribed me an oral medication for it. Oh, and I had another HIV test. Negative again.

After that I went to an infectious disease doctor who took a vial of my blood and sent it out to be tested for various diseases. He also told me to stop taking the medications from the ER and urgent care if they didn't work. I was happy to oblige.

A week later, I returned to his office for my results.

Negative across the board. My infectious disease doctor then decided I needed even more testing, and took five more vials of my blood. *Five!* I was tested for every possible infectious disease known to the medical field, and when I returned to his office over a week later for the results, I received one unanimous result: negative. I was beginning to think I was the next Lou Gehrig!

But then, a light: my infectious disease doctor said he thought I might have something called pemphigus. However, since pemphigus is not an infectious disease, he couldn't make that diagnosis nor test me properly for it. He was technically not even "allowed" to allude to something like that, but I think he could see the loss in my eyes.

He continued to tell me it's an extremely rare autoimmune disease that bears many forms, but can only be diagnosed by an oral surgeon. (Not true: a dermatologist can test for it, too. Trust me. My dermatologist cut a piece of my vagina off and sent it to a lab to be tested months after this.)

I decided to pick the youngest oral surgeon known to man on Long Island. Hey, he was on my insurance. (And I was sick of old, white men staring at me in a confused state.)

It was now the last weekend of August, and the day of my nephew Zachary's birthday party. I was to meet up with my family there, after my appointment with the oral surgeon.

Could I just go back to crying while brushing in the bathroom?

The joke was on me. The next thing I knew, tears were pouring down the sides of my face as I lay back in the chair, no longer able to take the emotional and physical stress of the situation, as a guy who couldn't be more than 24 years old was hunched over my face, cutting a healthy piece of my tongue right off. *Right off!*

I never met up with my family

that day. But I have an angel in my life, and that angel left her grandson's birthday party, took care of me, and bought me a chocolate milkshake. (Thanks, Mom.)

By early September, the results of the Great Tongue Hacking of 2016 had finally arrived. My devastatingly young oral surgeon confirmed that the disease taking over my mouth, and likely my esophagus, was pemphigoid (basically, a family friend of pemphigus.) And more specifically, it was *probably* mucus membrane pemphigoid. But that's another test.

If you're counting, that was over two months of keeping up appearances while feeling like the Million Woman March was trampling my mucus membranes.

After several trips to the ENT and gastroenterologist, and one endoscopy later, it was confirmed my esophagus was riddled with lesions. And after one excruciatingly painful visit to my OBGYN, I experienced what no female ever wants to hear an OBGYN say: "Um . . . I'm going to have to call a colleague [long pause]. I just don't know what to tell you [confused look, shakes head.]"

After that, the search was on to find a doctor who knew what pemphigoid was, could determine its type, and tell me how to treat it. And that's when I realized: this wasn't the end. It was only just beginning.

Tina Santomauro is an MMP patient living in New York City. She's also a person. She currently works as an original programming and development executive in comedy television.

Support Group Updates

Becky Strong

When dealing with pemphigus or pemphigoid, you frequently feel like you're doing it alone. This makes regional support groups very important to the IPPF. There is something about sitting in the same room and being with somebody who "just knows" what it's like.

This year has already been a busy one, as two new groups held their first meetings. Our newest group, in Buffalo, NY, met for the first time on April 1, 2017. This meeting was organized by Lisa Ann Krutzik and sponsored by Karen Easton of NuFactor Specialty Pharmacy. Dr. Kristina Seiffert was the guest speaker. She discussed the work she is doing with Dr. Animesh Sinha on her current research project, how to get involved, and the importance of patient blood donation.

The Mid-Atlantic Support Group held their first meeting in early February. Organized by Carolyn Fota and Kevin Kreutner, the group was sponsored by Diplomat Specialty Pharmacy. Vicky Starr was their guest speaker. They had a wonderful lunch and are making plans for their next meeting.

Our established groups have been hard at work as well. The Tri-State Support Group had a meeting on March 19 in New York City. Esther Nelson, group leader, said they

discussed the direction their group would like to take moving forward. They also spent time in small group discussions talking about many of the issues faced by those affected by pemphigus and pemphigoid.

The South Florida Support Group held a meeting on April 23 at the Spanish River Library in Boca Raton. Nancy Corinella, their group leader, invited Dr. Angela Weatherall to speak to their group about rituximab treatments.

The Houston Support Group met on April 1, and MaryLee Jackson coordinated a great lunch and discussion for all at the Bayland Community Center in Houston, TX.

Boston Area Support Group, lead by Ellen Levine and Sam Iwamoto, met at Panera Bread on April 29. I attended this meeting to talk about the services offered by the IPPF.

If you are interested in our support groups, please contact me at becky@pemphigus.org.

More information on upcoming meeting can be found at pemphigus.org/events.

Becky Strong is a PV patient and the IPPF Outreach Manager. She was diagnosed in 2010, but is currently in remission. She lives in Michigan with her husband Tim and her young family.



A History of Support in SoCal

Mei Ling Moore

When Janet Segall founded the IPPF in 1994, an email discussion group was used to facilitate daily communication between patients. It was a great way to find others and ask Janet questions. Before social media took off, this was the only means of online communication for pemphigus patients.

Several years later, Janet organized the first LA Support Group Meeting at UCLA. She thought it was important for patients to meet others with similar experiences.

The meetings became an annual event. Since Janet was in Sacramento, Sonia Tramel and Lee Heins (current and former IPPF board members, respectively) handled the logistics in Southern California. Marc Yale, who at that time was not only a patient, but also an advocate who went to government offices to raise awareness of pemphigus and pemphigoid, also helped organize the event.

Subsequent meetings were held on the Westside of Los Angeles, and now our meetings take place at the Santa Monica Library. We first enjoy a catered lunch, and then our guest speakers address the group and answer questions. Over the years, we've had a wide range of guest speakers, including dermatologists and a professor of dentistry from UCLA. Particular highlights have included Dr. Jennifer Haley (who started the Pemphigus Clinic in the Dermatology Department at UCLA) in 2002 and Dr. Sergei Grando in 2013. Once in a while, the IPPF Peer Health Coaches take center stage, and we take questions from everyone.

Topics of discussion at our meetings have included

skin and oral blistering issues, new therapies, and clinical trial results. Patients have met with visiting doctors after the meeting to privately ask questions that would have been too delicate for group discussion.

Marc Yale coordinates with Kroger Specialty Infusion, who sponsors the meeting. After the support meeting ends, participants often enjoy visiting the Santa Monica Pier and the Third Street Promenade.

I became involved in organizing the meetings in 2014, and I'm happy to do it. When the patients show up, it's like a reunion, and their smiles light up the room! New patients are made to feel extra special because the "oldies" offer support and plenty of their own experiences to show that no one is alone; we all share similar challenges that can definitely be met. Those who are in remission offer great hope to everyone still going through treatment and just trying to get through their day.

Our next meeting will be held on May 20, 2017, from 11:00 a.m. to 2:00 p.m. If you're in the area, please join us at the Santa Monica Public Library. David Woodley, MD, of USC and Janet Fairley, MD, of the University of Iowa will be our guest speakers. Lunch will be provided.

For more information, please contact Becky Strong at becky@pemphigus.org.

Mei Ling Moore has been an IPPF Peer Health Coach since 2012. In her old life, she was an executive assistant in TV production and worked at major talent agencies. She has also worked at vet clinics, as she loves dogs. Mei Ling lives in Los Angeles.

Living in a Bathtub

Terry Wolinsky McDonald, PhD

Maybe none of us have had to literally live in a bathtub, but pemphigus and pemphigoid patients have faced many obstacles. As most patients know, prior to the introduction of prednisone in the 1960s, doctors didn't have effective medication available to treat certain diseases. Nothing worked. Antibiotics and other treatments were thrown at patients, all of which did nothing to enhance quality of life or lifespan.

I received my own pemphigus diagnosis in 2001 after more than nine months of serious symptoms. With the knowledge of my preexisting stomach condition, my doctors soberly told me that I might have only six months to live. They knew I could not even tolerate five milligrams of prednisone, and that taking 40 milligrams or more was not an option. My response was to do my own homework. I put aside emotions and went into academic/research mode as I haunted medical libraries, reading every book and journal I could get my hands on in order to educate myself and my doctors on possible alternative treatments for my own special circumstances.

For the first seven years after receiving my diagnosis, I received specialized treatments from a dermatologist who was willing to try anything that worked after talking with experts and reviewing medical research.

She had some experience with pemphigus, but never had a patient who was unable to medically tolerate prednisone. We had a caring and respectful relationship, which allowed her to work with me and to speak with any and all recommended experts. It was an excellent collaboration. I'm thankful for the experts who gave their time and expertise so graciously. One in particular—you know who you are.

In 2002, I contacted the media about my diagnosis in Pittsburgh, PA, and was the lead story on the local news (repeated several times the following weekend). Several undiagnosed patients recognized their own symptoms and sought the help they needed. At the time, I was receiving monthly infusions in one particular hospital on the outpatient procedure floor. Two very sharp nurses saw a woman brought in by her husband for a biopsy. The woman was in serious pain. Her skin was falling off, and she was practically incoherent. I later found out she had spent the previous couple of weeks in a bathtub because it was the most comfortable place for her as she waited to die. The nurses noticed that this new patient seemed to have symptoms very similar to my own. They asked her husband if she had been tested for pemphigus vulgaris. Like most people, he had never heard of it, but he was encouraged to ask the doctors to test for it. He and the doctors followed

through, and the woman was put on high doses of prednisone (that were eventually tapered) and ate healthy, non-triggering foods. To my knowledge, she has remained in a very long remission.

This January I attended an event with about 40 of my high school classmates in southwest Florida. We planned the event due to the success of our 50th high school reunion in 2015, during which about 300 of my former classmates from more than 30 states gathered in Pittsburgh. At the event, I found myself talking with a small group of people. Among them was a former classmate who had recognized me at a psychology conference about seven or eight years ago. He was working at the hotel and at the time we hadn't seen each other in more than forty years.

During the conversation in January, a psychiatrist classmate began discussing the relative of the man I had connected with at the psychology conference. He remembered that they used to visit his relative who "lived in a bathtub" with water up to his neck. The response was that it was mostly true and the relative had pemphigus vulgaris! The psychiatrist classmate had never heard of the disease, and I explained that

I've had this disease for 17 years. What are the chances of this? Pemphigus vulgaris is such a rare, ultra-orphan disease. We had not seen each other in almost 52 years, yet my classmate happened to have the vague memory of visiting another classmate's relative who seemed to live in his bathtub (a reality prior to the availability of prednisone).

The great news is that after about 20 years of spending a large amount of time in the bathtub, the relative was able to live a fairly normal life after the advent of prednisone. However, he had to learn to live in the real world very slowly. He earned a college degree, married, and had a successful career. He lived to be 90 years old and did not die from pemphigus! I love this story. What are the odds? We are lucky to be living with these diseases now. We're not living in bathtubs, and this man's survival was a miracle.

Terry Wolinsky McDonald, PhD, is a PV patient, clinical psychologist, and former IPPF Board member living in Pittsburgh, PA and Sarasota, FL. She is a regular contributor to the Quarterly newsletter in her "Psychologically Speaking" column.

IPPF Scientific Conference

Lübeck, Germany

June 21-23, 2017

The 2017 IPPF Scientific Conference will bring together clinical and scientific experts in the field of autoimmune bullous disorders. The conference is an opportunity for physicians and scientists from around the world to come together under the common goal of studying pemphigus and pemphigoid. This will be the first IPPF conference held outside the United States.

Registration & more information at pemphigus.org/lubeck2017

Collective Hope at the NIH

Debra Ann Levinson

The National Institutes of Health (NIH) in Bethesda, Maryland, is a 70-acre biomedical facility where discoveries in cellular biology and genetics are made. It's also where advancements in drug-treatment options are made, and it's the only place I'd want to be on Rare Disease Day. Now, more than ever, patients are able to provide information about what they want—and don't want—from medications. The “patient voice” encourages pharmaceutical development to better define quality-of-life outcomes.

The morning of Rare Disease Day 2017 began aboard a bus to Building 10 at the NIH, filled with the anticipation of gaining new knowledge. Presentations from clinical directors, chief scientists, and principal investigators would soon be underway. At the NIH, the morning included remarks, progress reports, and updates. Among a lot of technical information, the talk



RARE DISEASE DAY 2017

of speedier research timelines stood out. For example, modeling human disease through technology using Zebrafish instead of mice may decrease lead time for validating results. There was also discussion of task forces for global exchange of disease commonalities. However, the details on how that data could be broadly shared are still uncertain.

Throughout the day, we heard from patient advocates and courageous families who shared difficult journeys into worlds of doctors and hospitals. Any talk of remission or stable conditions brought rooting and applause. Congressional staff spoke of their support to increase funding for research programs. With the recent passage of the 21st Century Cures Act, the allocation of those resources could make drug development even faster.

Three hundred patients from 48 states still went home with the reality of chronic illness. Yet the takeaway was the sense of a healthier tomorrow, confirmed at the NIH that February day. The theme of observance was very impactful: “Research brings hope to people living with a rare disease.”

I love the NIH and can't wait to go back next year (not only because of its gift shop).

Debra A. Levinson is an MMP patient, diagnosed in 2015. She lives in New York with her husband, Bruce.





Patient Advocates with Rep. Jerry McNerney at Rare Disease Week

RARE DISEASE DAY 2017



A recap on how advocates made an impact for rare diseases

Rare Disease Day was recognized in the United States for the tenth consecutive year on February 28, 2017.

Advocates and rare disease community members worked hard in the United States to recognize the day and create change for people living with rare diseases. The theme of the day was "With research, the possibilities are limitless."

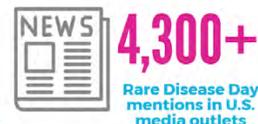
NORD SPONSORED EVENTS



NORD worked with advocates, medical students, and medical professionals to host academic and advocacy events across the United States.



Community Participation



NORD is thankful to the advocates, volunteers and sponsors who made Rare Disease Day 2017 possible.

To view photos from these events and learn more about Rare Disease Day, please visit rarediseaseday.us



Doris Chenier advocated for the concerns of P/P patients at the office of her state's representative, Congressman Cedric Richmond (LA).



Carolyn Fota came prepared for Rare Disease Week.



Rare Disease Day® is sponsored and hosted in the U.S. by the National Organization for Rare Disorders (NORD)®. NORD is a member of the National Alliances, a group of umbrella organizations that work with Rare Disease Day founder, EURORDIS, to organize and present Rare Disease Day around the world.

Join in for Rare Disease Day 2018!



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A wide-angle photograph of a long wooden pier extending into the ocean. The scene is captured during sunset or sunrise, with a warm, golden light reflecting off the water and the sky. The pier's structure is silhouetted against the bright horizon. The ocean waves are visible in the foreground, and a few people can be seen walking on the pier in the distance.

2017 IPPF Patient Conference

Newport Beach, CA

September 15-17

More info soon at pemphigus.org

Quarterly

Journal of the International Pemphigus & Pemphigoid Foundation