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Spreading awareness about pemphigus and pemphigoid (P/P) is one of the keys to our success, and so far P/P awareness efforts in 2018 have been greatly successful. After multiple biopsies and seeing more than my fair share of doctors, I remember wondering, “Why don’t more people know about these diseases?” Since that day in August of 2007, it was clear that I needed to do my part in making sure that more physicians, researchers, elected officials, and anyone else who would listen knew about pemphigus and pemphigoid. As illustrated in this edition’s article, “Hearing vs. Listening” by Terry Wolinsky McDonald, PhD, this isn’t always easy. However, with your support, we can achieve our goals!

As you will learn from Kate Frantz, we are truly “Banding Together to Spread Awareness.” Our reach has multiplied over recent years, and the IPPF has positioned itself to be an example for other rare disease organizations around the globe. Our presence continues to grow as the IPPF leads the way in educating existing and future medical professionals; our Patient Educators travel coast-to-coast sharing their stories; and Awareness Ambassadors like Fred Wish (NJ) and Carolyn Fota (VA) spread the word through in-person visits to dental offices and online activities. Our community continually aims to increase P/P symptom recognition among dental and medical professionals, thereby decreasing diagnostic delays and resulting in better patient outcomes.

We have made some impressive strides in generating awareness, but we still have a long way to go. Spreading awareness about our diseases will lead to increased research, better treatments, improved access, and (one day) a cure. I hope you will join me as we band together to put P/P on the RADAR of all dental and medical professionals! Enjoy this edition of the Quarterly, and I encourage you to get involved in spreading awareness.

Thanks for your support!

Marc Yale
IPPF Executive Director and MMP Patient
marc@pemphigus.org
Banding Together to Spread Awareness

Kate Frantz

It's been a collaborative effort to bring the Awareness Program to where it is today. We certainly could not do what we do without the support from our community.

Patient Educators share their stories at dental schools; local volunteers lend countless hours at exhibit events; guest contributors write articles for PemPress and the Quarterly; dental professionals provide continuing education courses across the country; and 54 Awareness Ambassadors educate dentists, family, and friends in their local communities. It is incredible to see the passion and energy among our community as we band together to spread awareness of pemphigus and pemphigoid (P/P). This teamwork has enabled us to make significant progress in the dental community, providing outreach to over 15,000 dental professionals and students—in person—since the Awareness Program began.

Let me take you on a journey over the past four years, showcasing the fruits of this collaboration and our efforts to reduce P/P diagnostic delays by “putting P/P on the radar” of dental professionals.

Patient Educator Presentations at Dental Schools

P/P patients share their emotional diagnosis journeys with dental students across the country. To date, Patient Educators have provided presentations at 18 schools reaching roughly 5,500 students! Check out our Patient Educators in action by watching this video: http://pemphig.us/pe-highlights.

In-Person Continuing Education

Both patient and scientific speakers present continuing education (CE) courses on P/P to dental practitioners. Often speakers present together, providing a unique presentation in which the audience hears scientific information along with the patient story. The IPPF has presented 19 CE courses, reaching almost 1,000 dental professionals.

Online CEs

The IPPF collaborated with Paradigm Medical Communications on an online CE module, Diagnosis and Treatment of Pemphigus Vulgaris: Strategies for Optimal Multidisciplinary Care. Be sure to check out the course and tell your dentist about it: www.pemphigus.org/awareness/dental-ce/

Exhibiting at Dental Conferences

The IPPF exhibits 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 IPPF. We have exhibited 18 times, reaching roughly 8,500 dental professionals.
Articles in Dental Magazines, Journals and Websites
The IPPF seeks opportunities to publish articles on P/P to increase the reach of our messaging. Fifteen dental societies in eight states have accepted our article on P/P for publication in their various newsletters and social media outlets. Most notably, we’ve published information related to pemphigus and pemphigoid awareness in the Journal of Dental Education, the American Dental Hygienists’ Association’s Access magazine, the Washington Post, Rare Disease Report, Dentaltown magazine, Harvard’s Undiagnosed Disease Network, and many others.

Online and Print Educational Resources
Have you been to the Awareness Program’s website, PutItOnYourRadar.org? This site is specifically for dental professionals. We have a resource page, videos, and materials available for print. Our newest resources include info cards about our Patient Educator Program and Continuing Education opportunities, as well as a video highlighting our professional courses offered to dentists and dental hygienists. Make sure to tell your dental provider about our site.

Search Engine Optimization
Generating fresh content on our website is one way to improve our search engine optimization, making it easier for patients and doctors to find us online. One way we do this is through our news site, PemPress: pempress.com. You’ll notice a whole section dedicated to the Awareness Program. Be sure to check it out.

Eblasts 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 resources, this

Help us reduce diagnostic delays by putting P/P ON THE RADAR of dental professionals!
Tear out this info card and give it to your dentist at your next dental appointment.

What are Pemphigus & Pemphigoid?
Pemphigus and pemphigoid (P/P) are rare, autoimmune blistering diseases that affect the skin and mucous membranes.
Pemphigus vulgaris (PV) and mucous membrane pemphigoid (MMP) are two forms of P/P that commonly present with oral lesions.

Delayed Diagnosis
Average patient sees 5 doctors over 10 months in search of a P/P diagnosis.

Clinical Presentation
• Think of PV/MMP when a patient presents with multiple, chronic, non-healing ulcers or blisters
• Lesions can also occur outside the mouth
• Lesions can follow a minor trauma (Nikolsky Sign)
serves as an additional communication method. Ask your dentist to join our list!

**Awareness Ambassadors**

Our Awareness Ambassador Program has officially launched! We have 54 Awareness Ambassadors who generously volunteer their time to spread awareness in their local communities. We currently have two activities available for Ambassadors:

1. Distributing Materials to Dental Offices
2. Spreading Awareness Using Facebook

If you are interested in becoming an Ambassador, visit [www.pemphigus.org/awareness/ambassadors](http://www.pemphigus.org/awareness/ambassadors).

**Joining FNIDCR PAC**

The IPPF had the privilege of joining the Friends of the National Institute of Dental and Craniofacial Research (NIDCR) Patient Advocacy Council (PAC). This Council, supported by the American Association for Dental Research, is comprised of nonprofit organizations who work together to 1) support oral health research and NIDCR and 2) transfer oral health research from bench to bedside.

**Interdisciplinary Education**

The IPPF recently received $2,000 in funding from Genentech to educate interdisciplinary student audiences about P/P. With this funding, the IPPF has the opportunity to provide Patient Educator presentations to medical, nursing, and dermatology students. We look forward to updating you on our progress.

**Evaluation/Data Collection**

The Awareness Program is all about data! We conduct surveys with dental students after each presentation. Preliminary data revealed the majority of students felt the patient’s testimonial would help them to remember important facts about P/P (94 percent...
reporting VERY or SOMewhat strongly). Likewise, 97 percent of students felt the patient’s testimonial would influence their future clinical decision making (97 percent reporting VERY or SOMewhat strongly). Here are a few quotes from students:

"Awesome presentation. All dental students should have the opportunity to have this lecture."

"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."

“When the patient stopped smiling because of her condition. This is something that stood out to me the most because I’m in the field of dentistry. Our main goal is to help maintain any patient’s oral health, but a personal goal for me is for every patient to love their smile. It is something to be proud of that plays a major goal in someone’s self-esteem. It was heartbreaking to hear that someone lost their love to smile because of this condition.”

We also surveyed dental professionals while exhibiting at conferences. Preliminary results revealed that 44 percent of dentists and 55 percent of dental hygienists reported low confidence levels in their ability to recognize the clinical presentation of P/P. We will continue to track this data and hope to see confidence levels rise in years to come. For a detailed report, turn to page 10.

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 Dental Advisory Council and Content & Curriculum Committee for their review, feedback and scientific support of this Program.

This quarter, the IPPF is raising funds to specifically support the Awareness Program. Keep a lookout for a letter in the mail with instructions on how to donate. Or, as always, make your gift online: www.pemphigus.org/donate.

\[\text{Kate Frantz is the IPPF Awareness Program Director. She lives in Michigan with her husband.} \]
While people think they objectively see when their eyes are open, this may not always be the case. Nor do they always hear what’s being said when others speak. Concentration, focus, interest, agendas, and preconceived notions are all factors that determine our perceptions of what we see and hear. As a trained psychologist, I’m used to reading people. This involves both verbal and nonverbal language. Interestingly, most human communication is non-verbal. Understanding and recognizing this is helpful when the words coming out of someone’s mouth do not match their body language.

When I am asked to explain P/P to a doctor, dentist, friend, family member, colleague, or new acquaintance, I generally give the explanation that my B-cells miscommunicate with my T-cells; they think parts of my body are the enemy and attack. I also write down the IPPF website: www.pemphigus.org. Most people don’t look it up, but if they do and contact me afterward, I’ve found that I’m more likely to have a positive and satisfying conversation. And one more person is now aware.

Although P/P awareness efforts have improved, it’s important to continue educating doctors and dental professionals so they can recognize symptoms and provide treatment. Many dentists only know the name of these disease and a few symptoms, and they often don’t recognize them or know the precautions to take while providing specialized treatment.

My own diagnosis story is a perfect example. I went undiagnosed for almost an entire year in 2001. I consulted with my primary care physician, general dentist, three oral surgeons, two periodontists, an oral pathologist, an ophthalmologist, and other medical specialists. They were unable to narrow down the diagnosis, and biopsies were only tested for cancer. I was finally properly diagnosed with pemphigus by a dermatologist whose father had been a dentist!

After my diagnosis, I was very motivated to make sure this didn’t happen to others, and within a year I
appeared on a local television channel in Pittsburgh with their savvy medical correspondent. The segment was repeated over the weekend, and I know of at least one life that was saved because of it. Additionally, a couple other patients were diagnosed faster because they, or people they knew, had seen the segment. Due to the personal and simple (but direct) format of the television segment, it was relatable. I clearly remember what the medical correspondent said to me when I pitched my idea: “I want to make sure you understand that if you do this, you will be totally putting yourself out there. Are you okay with that?” I immediately responded “yes,” because I knew I would regret it forever otherwise.

If you are uncomfortable totally putting yourself out there, please know there are many other ways to help in the IPPF Awareness Program. Just contact the IPPF, and they will be happy to help you help all of us.

My first continuing education presentation at the University of Pittsburgh Dental School was called, “Pemphigus and Pemphigoid: What You Don’t Know May Kill Someone.” I have since presented at various dental schools where the groups have listened, watched intently, and asked excellent questions. Yet only one seasoned dentist has followed up with me after doing a biopsy and properly diagnosing an oral pemphigus case. He admitted that he had no idea whether or not he’d seen pemphigus before, and that if he had, he probably would have just prescribed a special mouthwash.

Please contribute to the ongoing IPPF Awareness Program in any way you can. The IPPF and some remarkable individuals have been working tirelessly to spread awareness of P/P. Informative presentations directed at dental professionals remain invaluable. Visits to elected representatives both locally and in Washington, DC, are important. It is harder to ignore people standing directly in front of you, and emails and letters must continue to be written. My hope is that more and more professionals, elected professionals, and the general public will truly hear us. There is greater strength in numbers, and every one of us is important.

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 in her “Psychologically Speaking” column.

Help us reach our Awareness Program goal of raising $30,000 by June 30!
Make your gift today at www.pemphigus.org/donate
2017 PRELIMINARY DATA
Surveys Among Dental Professionals

The IPPF surveys dental professionals while exhibiting at dental conferences across the U.S. The following data was collected from 2015-2017 at 11 dental conferences.

Self-reported Confidence Levels
(From 245 dentists and 153 dental hygienists)

Recognizing Clinical Presentation of P/P

- Dentists: 44% Low, 37% Somewhat, 19% High
- Hygienists: 55% Low, 31% Somewhat, 14% High

44% of dentists and 55% of dental hygienists reported low confidence levels in their abilities to recognize the clinical presentation of pemphigus and pemphigoid.

Providing Routine Care to P/P Patients

- Dentists: 49% Low, 31% Somewhat, 20% High
- Hygienists: 48% Low, 29% Somewhat, 23% High

49% of dentists and 48% of dental hygienists reported low confidence levels in their abilities to provide routine care to a patient with a pre-existing P/P diagnosis.

Average Number of P/P Patients Seen by Dentists and Dental Hygienists: Compared by Confidence Levels

- Low Confidence: 4
- High Confidence: 14
Dentists and hygienists want to learn more about P/P and are especially interested in online CE courses.

**Have You Heard of the IPPF?**
Dental Professionals (673 total)

- **Yes**: 83%
- **No**: 17%

**What does this all mean?**
A swift diagnosis is essential for P/P patients. Approximately two-thirds of P/P patients experience oral symptoms first, providing the dental practitioner with a unique opportunity to render an early diagnosis. Almost a quarter of patients will see a dentist first when seeking a diagnosis and roughly half will see a dentist at some point during their diagnostic journey. Unfortunately, patients are often misdiagnosed and referred to multiple healthcare providers, delaying diagnosis and treatment.

Our surveys show that a large percentage of dentists and dental hygienists report low confidence levels in their abilities to recognize P/P. Those reporting “low confidence” often see significantly fewer P/P patients than their “high confidence” colleagues; one hypothesis is that they may in fact be seeing P/P but fail to recognize it. In addition, a large majority of dental professionals have never heard of the IPPF, missing the opportunity to refer patients for necessary support services and resources.

This data suggests the strong need for continued outreach to the dental community. Our work here is not done. The Awareness Program hopes to see a rise in confidence levels as we continue our efforts to reduce patient diagnostic delays.
I first learned about the Awareness Ambassador program when Kate Frantz, IPPF Awareness Program Director, gave a presentation at the IPPF Annual Patient Conference a few years ago. Kate’s infectious enthusiasm and the obvious value of the program were compelling, and many patients and caregivers expressed an interest in participating.

The patients I spoke with told a familiar story: months of worry, both for themselves and on the part of their loved ones; months of confusion and fear about what was happening to their mouths and skin; months of seeing an assortment of family doctors, dentists, dermatologists, and other practitioners; and months of worsening and more frightening symptoms. As I’ve since learned, it takes an average of 10 months for a pemphigus or pemphigoid (P/P) patient to receive a definitive diagnosis. Some of the patients I talked to had gone years without a diagnosis, or they received the wrong diagnosis and were treated for the wrong disease.

I was more fortunate than most. It took only seven months after my first lesions appeared to receive an accurate diagnosis of pemphigus vulgaris (PV) and I could begin effective treatment. The first dermatologist I consulted with about scalp lesions (which I did not connect to the raw patches in my mouth) told me it was seborrheic dandruff and prescribed an alcohol-based lotion to apply directly to the open sores on my scalp—an excruciating experience. But, he was the doctor, so I endured the pain and tried it a few times. I stopped after realizing there was no improvement. My dentist, Alan Cohn, and his oral surgeon partner, Ira Port, literally saved my life by correctly identifying my PV and setting me on the path to treatment. Alerting dental professionals about P/P can help patients avoid some of the delays and fruitless treatment regimens that others have endured.

It is logical that an earlier diagnosis means earlier proper treatment, and that earlier treatment improves the probability of successful healing and management of symptoms. When Kate Frantz and Bryon Scott, IPPF Awareness Ambassador Coordinator, announced the rollout of the Awareness Ambassador Program at the 2017 Patient Conference in Newport Beach, it was an easy decision to sign up and visit dental professionals in my area. The required online training was useful in that it not only provided suggestions on what to say, but also on what not to say when approaching dentists and other healthcare professionals about P/P. I was surprised by the number of dental offices within just a few miles of my home. It’s similar to what happens when you buy a new car: suddenly you see that same model everywhere you look. When you are attuned to look for them, dentists are everywhere.

When I first volunteered as an Awareness Ambassador, I expected it to be more time consuming. It turns out that it’s an easy matter to drop into a dental office and chat with the dentist, hygienist, or dental assistant about their potential role in an early P/P diagnosis. I was able to make four contacts within my first two hours as an Awareness Ambassador in my community, and my experiences since then have yielded

Fred Wish

Awareness Ambassador
A PERSONAL PERSPECTIVE
similar results. Regrettably, I haven’t reported those results back to IPPF as diligently as I could have; I’ll try harder to do that in the future.

Having spent a few years in sales, I was anticipating a lot of rejection. Frankly, I expected that most of my encounters would be with front-office staff and consist of merely dropping off materials and contact information. However, this has not been the case for me. Dentists and hygienists have been remarkably receptive to hearing about P/P and the support the IPPF is able to provide for their symptomatic patients. Many of them were somewhat familiar with PV, but were eager to obtain more information about it and other bullous diseases. One dentist I encountered conducts online training programs for members of the American Dental Association and expressed a strong interest in presenting a podcast on pemphigus and pemphigoid, which could reach several hundred dental professionals. I put him in touch with the IPPF to work out the details. This connection might not have happened without the Awareness Ambassador Program.

Visiting dental offices may not be everyone’s cup of tea—does anyone really like going to the dentist?—but the IPPF is rolling out other initiatives through the Ambassador Program, such as “How to Spread Awareness on Facebook.” You can get information about new outreach activities by visiting www.pemphigus.org/awareness/ambassadors. You may find an opportunity that motivates you to help spread awareness.

None of us asked for this disease to become a part of our lives, but being part of the solution by raising awareness with the goal of getting patients into treatment faster gives us a measure of control. It’s a positive way to fight back at P/P and satisfy our need to be a part of something larger than ourselves.

Fred Wish retired in 2010 from a career in corporate communications and regulatory enforcement. When he’s not traveling or playing in a classic rock band with his wife, he operates a writing and editorial services company at the Jersey shore.

Carolyn Fota lives in Stafford, VA, with her husband, Frank, and their three crazy cats. Carolyn enjoys walking, yoga, church, and writing.

As an Awareness Ambassador with the IPPF, I was excited to see the release of a new activity, “Spreading Awareness on Facebook." I immediately signed up just in time to help spread awareness of Rare Disease Week 2018, which I was also fortunate enough to attend in DC. Spreading awareness of this event through Facebook was fun and easy, and it allowed me to engage with people while in DC and back home in Virginia.

The process for signing up to support the IPPF with this outreach was easy. I received notification via email with simple instructions on how to support an event, in this case Rare Disease Week. I followed suggestions for posting messages, images, links, and sharing information. It seemed that every new person I met during Rare Disease Week was either taking a picture, writing something, or posting. It really was fun and I made a lot of friends.

I posted information about Rare Disease Week on my Facebook profile, and I was surprised to see the IPPF community, friends, family, and even colleagues from work following me. I had one family member call me at my hotel and ask for my schedule the next day so she could follow what was going on.

By the end of the first day of Rare Disease Week, I had many people who “liked” and “loved” my posts, and I received a bunch of comments from old high school buddies, friends, family, and colleagues at work. Through this activity, I learned a lot about writing, taking pictures with my phone, inserting hashtags, and sharing with people around me.

In the midst of this fun, I was able to build awareness of Rare Diseases, Rare Disease Week, and the IPPF. I look forward to participating in future IPPF Facebook outreach assignments!

Anyone interested in signing up to become an Awareness Ambassador can learn more online at: www.pemphigus.org/awareness/ambassadors
Traveling to Washington DC to represent pemphigus vulgaris (PV) patients during Rare Disease Week on Capitol Hill was both enlightening and discouraging. I realize the world often wants us to project the positive while sweeping the negative under the rug, but many of us with this disease feel we’ve had that rug pulled out from under our feet.

The first night I attended a documentary screening and reception of *The Ataxian*. I was in a ball of tears as I did my first Facebook Live broadcast later that evening. I explained to my friends and followers that although I’m in partial remission thanks to the advances of Western medicine and the ability to participate in a research study, most of the people I met that night weren’t able to say the same.

Kyle Brant and Sean Baumstark have Friedreich’s Ataxia, a debilitating, life-shortening, degenerative neuro-muscular disorder ([www.curefa.org](http://www.curefa.org)). Kyle’s trademark saying is, “Life is about how we react.” Sean’s motto is to do what he can, while he can, simply because he can. Together with two additional long-distance bicyclists, *The Ataxian* follows them as they participate in *Race Across America*, the “world’s toughest bike race.” The race goes from the shore in California to the shore in Maryland in less than nine days. The raw emotions throughout the film had almost everyone in the auditorium in tears.

There was one moment in particular that stood out to me during the film. Sean explained that when the doctor called to give him his diagnosis, he was asked to come in for an appointment a few weeks later. Since the appointment wasn’t immediate, Sean didn’t think it was serious and went alone. The doctor gave him the nuts and bolts of the disease and told him that he should start looking at adapting his house with hand grips and stabilizing rails. Waiting for the elevator on his way out, it hit him that soon he wouldn’t have the choice between taking the elevator or the stairs. So he decided to take the stairs while he could.

Rare Disease Week was enlightening on various levels beyond learning about the rare diseases that affect so many people. One in 10 people in America has a rare disease, and 95 percent of those diagnosed do not have an FDA-approved treatment. We learned about the Orphan Product Extensions Now, Accelerating Cures and Treatments, OPEN ACT (H.R. 1223, S. 1509); the Advancing Access to Precision Medicine Act (H.R. 5062); and funding at the National Institutes of Health (NIH). The following are my interpretations of how these acts may impact the IPPF community:

**OPEN Act (H.R. 1223, S. 1509)**

This act incentivizes drug companies to conduct research on existing drugs that could help other
diseases with similar characteristics. For pemphigus, rituximab is still an “off-label” medicine, which is one of the reasons it is difficult and expensive to obtain. This act allows the repurposing of drugs to treat a rare disease, which can lead to more research studies and eventual acceptance by the Food and Drug Administration (FDA). This act will help bring the cost of getting medications we need to survive and thrive down to market rate. This law also enables better access to drugs already in regular use for diseases like pemphigus and pemphigoid (P/P). Why would anyone be against this act? Because it incentivizes research by giving individual drug companies an additional six months of exclusivity on manufacturing these existing medications. This limits competition from other drug manufacturers in the short term.

Advancing Access to Precision Medicine Act (H.R. 5062)

This act encourages agencies to work together and allows for the use of genetic and genomic testing for people who are hard to diagnose, which would also be covered by Medicaid. As many P/P patients experience lengthy diagnostic journeys, we understand the monetary and emotional expenses. Imagine that your child is sick, and it takes 14 years to receive a diagnosis when it could have taken a few months if genetic and genomic testing had been available. This happened to a woman I met: her entire life became focused on finding a diagnosis and a way to stabilize her child. Genomic sequencing holds the potential to not only accelerate diagnoses, but also personalize treatments.

NIH Funding

The NIH could be key in resolving many rare disease mysteries, as one of its primary purposes is to provide a research database. Through one primary filter it can see potential similarities between diseases and key components to resolving them. For example, I spent time listening to people with narcolepsy, which is just short of being shown to be an autoimmune disease. As they shared some of their symptoms, I recognized issues that I, and others with PV, have had while on prednisone. The NIH would be able to cross-compare the symptoms and side effects during treatment of various autoimmune diseases. This could be helpful when dealing with side effects, treating actual symptoms, and potentially finding a way to prevent them in the first place.

The NIH was approved to continue operating, but without a new funding package. In order to be competitive, especially with enlisting the talents of top scientists, it has been proposed that the government increases funding to the NIH by $2 billion and the FDA by $2.8 billion.

The second component to the act is funding for the FDA. We are hoping that rituximab will be approved quickly since it has been fast-tracked by the FDA; however, they are so overwhelmed and under-funded that it may not be what most of us would consider “fast.” Getting the government to fund these entities correctly will have a major impact on all rare diseases.

I mentioned in the opening paragraph that this experience was also discouraging. It’s my opinion that the reason so many rare diseases need their own foundations who sponsor research studies is because there are no financial incentives for large pharmaceutical companies to invest the time and money needed in order to help less than a million people with a particular rare disease. There are only one or two people in the United States with some of the diseases represented during Rare Disease Week. It makes sense to me that an economy that emphasizes income over humanitarian needs would consider solving erectile dysfunction more important than figuring out how to stop a few peoples' bodies from killing themselves with an autoimmune disease. Granted, since autoimmune disease diagnoses have tripled in the last 50 years and continue to rise, maybe the general issue of autoimmune diseases may have as much pull as heart disease in the future.

I learned that we can’t count on the government to be the primary source of a solution. We need to support different foundations, do the legwork to raise awareness in our own communities, and be involved with every study, including electronic surveys. I also learned that awareness is the biggest piece of the puzzle at this point. Sharing information between our doctors, each other, and various industries is essential to enabling us to live longer, healthier lives.

Lisa Ann is a photographer, writer, entrepreneur, religious education director, and student of the world. PV shifted her perspective onto health and wellness. Find her blog at LARoxLife.wordpress.com.
It has been a little over 10 years since my father was diagnosed with mucous membrane pemphigoid and ocular cicatricial pemphigoid. There have been many scary and uncertain moments as he fought to get his disease under control and eventually in remission. However, I never thought that his diagnosis would lead to the opportunities it has for not only him, but for myself as well.

Four months ago, I had the opportunity to share my dad’s diagnosis story with a group of dental hygiene students at Pueblo Community College in Pueblo, Colorado. I was invited to speak to the first-year students in the college’s Dental Hygiene Program by one of the professors at the school. The professor explained to me that although he had briefly touched on pemphigus and pemphigoid (P/P) during his pathology lectures to his students in the past, he’d never had a P/P patient share their diagnosis story. Prior to talking with me, he had never heard of the International Pemphigus & Pemphigoid Foundation and did not know about the great resources the organization offers to patients, physicians, dentists, and dental hygienists.

As I wrote my speech, I relived ten years of painful memories. How was I going to get through my presentation without bursting into tears? I was extremely nervous. I also thought that my story would not have an impact on the students because I have no medical background and I am not a P/P patient. But as I rehearsed my presentation with Becky Strong, IPPF Outreach Manager, and Kate Frantz, Awareness Program Director, I discovered that my point of view of my dad’s diagnosis story was important. My dad’s journey from diagnosis to remission was my story as well. My story also included babysitting my younger sister while both my parents were away for numerous hours at doctor appointments and sitting with my dad at the hospital while he received infusion treatments.

I definitely had butterflies on the day of the presentation, but I knew that even if only a few students learned something from my presentation, I would make a difference. As I stood in front of the class, all my anxiety washed away. Telling my story was easier than I had thought. All the students smiled, laughed, and listened intently. They were all shocked to hear how long it took for my dad, and most P/P patients, to receive a correct diagnosis. Many of the students were also surprised to learn how many doctors he saw and that he was misdiagnosed multiple times.

Once I finished sharing my story, I explained to the students that they play an important role in decreasing
diagnostic delays for P/P patients. Dental hygienists have the majority of face time with patients. If they can recognize the symptoms of P/P, they can assist dentists with referring a patient for a diagnostic biopsy. A dental hygienist also plays an important role in providing patients with proper dental care in the future.

I also shared how important it is to remember that there is a whole person, each with their own story, associated with the mouth they are looking at. These students, who will soon be practicing dental hygienists, have the unique opportunity to change their patients’ lives by listening to their stories, concerns, and troubles.

After the presentation, I was amazed by the number of students who asked questions. They wanted to know more about P/P. Most importantly, they wanted to know how they could be sure to recognize P/P symptoms and help future patients. I know that I made a lasting impression on these students, and they will remember my story for years to come. In the future I hope to continue returning to this school and others so that I can educate more students about P/P. This is a unique opportunity for me to help all patients affected by these diseases.

You, too, have a unique opportunity to educate those around you about P/P. It might seem scary, but the reality may be easier than you imagine. You are the one with first-hand knowledge and experience. Whether you are a patient or a family member, you can share your story. The future will be brighter for patients and their families if we educate more people about P/P.

Amethyst Yale is the IPPF Outreach Assistant. She currently lives in Colorado Springs and is pursuing her master’s degree in public administration at the University of Colorado. Her father was diagnosed with pemphigoid 10 years ago.

Dear IPPF Family,

I have had the pleasure of working with the IPPF for a little over three years now. In this short time, I have been so richly blessed. I have experienced healing, self-growth, adventure, and made lifelong friendships. The IPPF has become my family, and volunteering has been the best journey thus far. After 18 months of remission, I’ve decided to embark on a new path. I will be taking a step back from volunteering as a Patient Educator while pursuing a new educational opportunity. I was recently accepted into a nurse midwifery program. I look forward to becoming a midwife and learning how I can incorporate my skills into helping our IPPF community.

I am amazed at all the IPPF has accomplished over the past three years. They have equipped me with the skills and opportunities to reach dental students, hygienists, and a broad range of other medical professionals. I have shared my personal story at dental schools across the United States and made lasting connections. I’ve volunteered at dental conventions in Florida, New York, and my home state of Oklahoma. Seeing the magnitude of the IPPF’s impact at these conventions has been sobering. I met with people from across the globe while listening and sharing countless heartfelt stories. One of my favorite moments was at our exhibit booth in New York when I met someone recently diagnosed with pemphigus. I was able to witness the excitement and passion of our volunteers as they immediately shared the hope and family connection that is unique to the IPPF.

Participating in Rare Disease Day on Capitol Hill was also empowering. I had no idea of the influence I could have with my legislators. What a privilege it was to sit with my Oklahoma senator and share my story.

The Annual Patient Conference is such a highlight for me and something I look forward to that brings all of us together. This past year, it was such an honor to attend and see everyone encouraging one another and sharing the latest growth, opportunities, and successes of our community.

I am truly thankful for all that the IPPF represents and the hope and support they provide. I cannot say enough about this wonderful foundation. I’ve found family and purpose while volunteering. I will be taking time away for education, but with every hope to come back again. My prayers and support will always be with you.

Sincerely,

Hannah Heinzig
The Aging Process is All in Your Mind

Kelly J. Calabrese

You never know how sick you are until you become well. We go through life taking care of our daily routines—raising children, going to work, reading the newspaper, eating meals on the run—and we don’t pay much attention to the big picture.

We never think of our bodies in the same way as we do our cars. If something goes wrong with the car—an odd noise, a stutter, fluid leakage—we bring it to the mechanic, and the car is fixed in a timely manner. However, when our bodies start doing weird things, we just let it go and go and go, until something very serious goes wrong. We may say, “Oh, that’s nothing, it’s just that we are getting older.” This is not accurate.

We need to think of our bodies in a different way. We only have one body and we cannot trade it in for a new model. When something goes wrong in the slightest way, we need to pay attention and take the little problem seriously, so as not to end up with a bigger problem down the road.

All the systems of the body work together and function as a whole. When one part of the body is in dis-ease, it’s only a matter of time before other parts become dysfunctional. Taking care of individual ailments is not going to solve the root cause; it’s just a Band-aid and a temporary measure.

Each person needs to discover what is going wrong with their body for themselves. By taking action to research possible causes of your pain, fatigue, emotional state, and injury, you will be better equipped to discuss options with your health care provider. Educate yourself so you can make an accurate decision regarding the care of your body. Get second and third opinions. Be persistent, and don’t allow the practitioner to intimidate you. You are paying for their service. You are in charge.

By discovering the root causes of your health challenges, you can alleviate many of those nagging problems, feel better, and look younger. Each day will have a different awareness of clarity, enthusiasm, and renewal. I wish all of you tremendous success on your personal discovery of the “Fountain of Youth”!

Kelly Calabrese, MS, CCN, is an Integrative Biochemical Nutritionist. She utilizes an 80-marker blood test to determine nutrient deficiency and get to the root cause of health disorders. She may be reached at (719) 590-9879 or fitfocus@qwestoffice.net. Her website is www.optimalwellnessLLC.com.

Thank you to the SY SYMS FOUNDATION and the UNGER FAMILY

For their continued support of the IPPF Awareness Program
What’s the Idea About ADEA?

Becky Strong

The International Pemphigus & Pemphigoid Foundation (IPPF) recently exhibited at a unique dental conference that put the Patient Educator Program front and center for dental educators. We were able to show the value of our program at the American Dental Education Association Annual Session and Exhibition in Orlando, Florida.

According to their website, “The American Dental Education Association (ADEA) is The Voice of Dental Education. Our mission is to lead institutions and individuals in the dental education community to address contemporary issues influencing education, research and the delivery of oral health care for the overall health and safety of the public.” (www.adea.org)

The focus of this year’s ADEA meeting was to examine what healthcare and health education will be like in the year 2030. The theme revolved around what can and needs to be done now in order to meet the demands of patients, patient care, the dental profession, and education so that providers are prepared to embrace all aspects of their global community in their practice today and in 2030.

As healthcare evolves and continues to take an interdisciplinary approach, it’s important that dental students realize the necessity to consult with other providers in different specialties. We pemphigus and pemphigoid (P/P) patients are classic case studies on how patients need a team of doctors to treat us and coordinate our care. Many of us see a primary care provider, dentist, dermatologist, oncologist or rheumatologist, ophthalmologist, and other doctors to get the care we need. The earlier dental students learn to communicate well with other specialists, the better care patients will receive.

IPPF Patient Educators travel to universities around the country and share their diagnostic stories. They openly discuss how their journeys continue with treatment, and how each doctor can make an impact on both patients and the dental community. As many patients develop oral lesions first, dental providers need to recognize the early symptoms of (P/P). By doing so, they reduce suffering and pain, as well as help patients receive timely diagnoses and treatment.

While exhibiting at ADEA, it was exciting to hear from faculty about how beneficial they feel the IPPF and patient experiences are to their students’ education. There were a number of times when, as we were trying to recruit a new school, a faculty member stopped by to give us an unsolicited positive endorsement. Additionally, faculty from schools where we haven’t presented at yet also visited our booth because a colleague told them they needed to learn more about IPPF Patient Educators.

So far in 2018, IPPF Patient Educators have spoken at four universities (Rutgers, University of Missouri Kansas City, Harvard, and Tufts), and have reached more than 500 dental students. Since the program began, our educators have shared their stories with almost 6,000 dental students and faculty at 18 schools.

Together, we are bringing P/P awareness to the brightest and best dental students in the country. But our quest is not finished. While we are planning to present at five dental schools this spring, we hope to bring the Patient Educator Program to new universities across the United States. Our hope is that one day every dental student will have P/P on their radar.

Becky Strong at ADEA

Becky Strong at ADEA

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.