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Quarterly

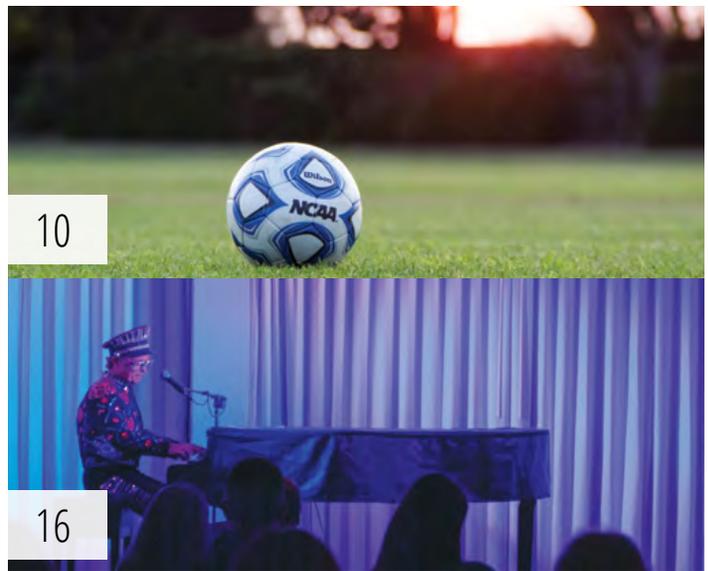
Journal of the International Pemphigus & Pemphigoid Foundation

*Patient Conference
Stories from Newport*

FALL 2017 • ISSUE #90

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FALL 2017



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Message from the Executive Director

When I learned that there was a foundation that supported a community of people like me after I was diagnosed with a rare blistering disease, I was astonished. I knew I wasn't the only one with the disease, but I certainly felt very alone. Corresponding with and meeting others in the IPPF community who were able to relate to my experience gave me hope. It was inspiring to hear the stories of those who had been through similar experiences. Equally inspiring was this year's Annual Patient Conference in Newport Beach. Hearing the heroic story of Kenny Metcalf and witnessing first-hand his triumphant performance was galvanizing.

Reading this "community" edition of the *Quarterly*, it's easy to see the legacy created by Janet Segall, the IPPF's founder. This ideal of community still unifies us today and drives all of our programs and services. Our community is the common bond we have with all those affected by pemphigus and pemphigoid. Together we can help others have better experiences than what we have gone through. This shared interest is what makes us increasingly resilient, and it will help us overcome adversity. We face many challenges ahead, and recent events in our interconnected world cause us all to feel overwhelmed. Collectively we must remain courageous like Jennifer Cavrudatz, pemphigus patient, and *Weather the Storm* (p.18)!

After reading *The Importance of Gratefulness* (p.6) by Dr. Terry Wolinsky McDonald, I hope you will realize that staying positive and relying on each other for support will affect all of our current and future community members. Staying engaged with the IPPF will help you feel less alone and more in control. I encourage you to reach out to your community. We are here to provide our experience and knowledge, and we are ready to advocate for you. I am so grateful to the IPPF community for being there when I needed it most, and I am honored to be assisting all of you now.

Gratefully,

Marc Yale
IPPF Executive Director and MMP Patient

marc@pemphigus.org



BANDING TOGETHER

1,000 Dental Offices in 90 Days

VISIT FIVE OFFICES IN YOUR COMMUNITY

Kate Frantz

The IPPF Awareness Ambassador Program officially launched in August with a lofty goal of visiting 1,000 dental offices by November 30, 2017. Awareness Ambassadors are IPPF community members who band together to spread local awareness of pemphigus and pemphigoid (P/P). Their goal is to help other patients receive a diagnosis faster. They do this by putting P/P on the radar of dental professionals.

In order to reach our goal, we need your help. The process is simple:

1. Visit us online to request more information: www.pemphigus.org/awareness/ambassadors
2. Review our online Ambassador Handbook at your own pace and then register to become an Ambassador.
3. Review our online training, “How to Distribute Materials,” then request materials.
4. Start visiting dental offices and update us on your progress!

We are looking for passionate individuals ready to spread awareness of P/P both in the US and abroad. This includes patients, friends, family, and healthcare providers, among others.

“I want to challenge the Awareness Ambassadors to complete the training and to visit at least five dental offices,” said Bryon Scott, Awareness Ambassador Coordinator. “In the process of reaching 1,000 dental offices, we are improving the chances for early detection.”

Are you ready to accept the challenge? Visit www.pemphigus.org/awareness/ambassadors for more information or email your questions to ambassadors@pemphigus.org

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

Tell Your Dentist About P/P Continuing Education

Kate Frantz

Will you help us spread awareness by telling your dentist about these continuing education opportunities?

A great way for dental professionals to learn more about pemphigus and pemphigoid (P/P) is through in-person and online continuing education courses. Since the start of the Awareness Program, the IPPF has provided 15 courses, reaching over 800 dental professionals in total. In an effort to expand these course offerings, we have created a new webpage highlighting our courses: www.pemphigus.org/awareness/courses

Dental professionals can visit our site to learn about upcoming courses or to request a presentation for their society or association. We offer presentations with strong emotional appeals to increase information retention. These special combined presentations feature both a patient and a scientific presenter. This

unique format gives audience members the chance to learn about the clinical presentation, diagnosis, and management of P/P from two perspectives.

You can also let your dentist know about online continuing education options by informing them of Paradigm Medical Communication's new online course, "Diagnosis and Treatment of Pemphigus Vulgaris: Strategies for Optimal Multidisciplinary Care" available here: www.pemphigus.org/awareness/dental-ce

It takes the average P/P patient five doctors and 10 months to obtain a correct diagnosis. Two-thirds of patients will experience oral symptoms first. By spreading awareness to the dental community, we hope to reduce patient diagnostic delays!

Continuing Dental Education

DIAGNOSIS AND TREATMENT OF PEMPHIGUS VULGARIS: STRATEGIES FOR OPTIMAL MULTIDISCIPLINARY CARE

This activity begins with a review of the presentation and diagnosis of pemphigus vulgaris, a rare but serious autoimmune disorder that is fatal if left untreated. Expert faculty further discuss current and emerging therapies for this challenging disorder, including clinical data, benefits and drawbacks, and strategies for safe and effective use to improve patient outcomes and quality of life.

This activity is provided by Global Education Group. UNLV School of Dental Medicine and Paradigm Medical Communications, LLC, are the educational partners.

www.pemphigus.org/awareness/dental-ce

The Importance of Gratefulness

Terry Wolinsky McDonald, PhD

Have you ever noticed that some people seem relatively happy, even in the face of great adversity, while others hunch over, sigh a lot, move slowly, and seem weighed down by great burdens? In reality, some people coping with difficult or complex illnesses and losses (including caregivers), make a conscious choice to look on the bright side. Others are so overwhelmed and numb that they feel paralyzed by negative feelings. This negativity can often be an unconscious choice.

Interestingly, the “choice” to be negative or positive will help determine a person’s level of resilience. Resilience is not necessarily a trait that people are born with; it is a cultivated attitude. The support and understanding found in our P/P community cannot be underestimated. The Dark Ages of these diseases are in the past, even with all of the challenges still to be faced.

Another tool that can help people facing the challenges of living with a rare disease is Motivational Interviewing (MI). MI is a therapeutic technique that allows people to decide what their subjective chances are of reaching a goal. Goals can be adjusted as necessary in order for patients/clients to experience small successes to build on, rather than shooting for the stars, continually coming up short, and feeling like a failure. It allows people to work from their own perceived strengths, and can serve as a major reality check. People often under- or overestimate what they can or cannot accomplish, and MI allows goals to be realistic, measurable, and doable. Being part of a community allows people to learn from each other. It also keeps things real!

Having ultra-rare orphan diseases and other illnesses afford patients, caregivers, and friends the opportunity

and challenge to live outside of their comfort zones. With these diagnoses come a new way of living in the world. While many doors seem to close, many previously unknown ones open, and the world is no longer the comfortable and predictable place it once was. Life can still be good, but it is not the same. Unfortunately, some people may go backwards to a world that no longer exists. Moving forward is the only way to grow and become the best person that you can be.

Attitude can either be instrumental or detrimental in a person's life. Attitude is another trait that isn't determined at birth; it is formed and changed over time. Flexibility allows a person's attitude to be a positive attribute. Choosing to be flexible and positive is a choice related to acceptance and gratefulness. Attitude, acceptance, and gratefulness are all malleable traits.

The most important take away from this article is this: When faced with the adversity that comes with chronic, rare, incurable (but treatable) diseases, no one is alone. There is a community to rely on, fall back on, and add to in countless ways. Yes, we all have weaknesses, but focusing on our weaknesses is unlikely to move us forward; it is more likely to paralyze us. We all have strengths that keep us moving forward, and participating in the IPPF community fosters positive thinking and gratefulness. Life is not always a roller coaster, but when it is, it can be a life-changing learning experience.

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.



Black Friday. Cyber Monday.

#GI  ING TUESDAY

November 28, 2017

This year, JOIN us as we launch a NEW way to SUSTAIN the IPPF MISSION.

Become a HEALING HERO.

Find out more at pemphigus.org



Holly Heinzig and Hannah Heinzig at the 2017 IPPF Patient Conference (Chris Gray Photography)

Building Community:

FLORIDA DENTAL CONVENTION

Hannah Heinzig

This year my mom and I had the pleasure of volunteering at the Florida Dental Convention with the IPPF. Visiting the exciting city of Orlando was an adventure, and I embarked on a new journey: the convention world! I was nervous to lead a booth at such a large gathering. Becky Strong (IPPF Outreach Manager) and Kate Frantz (IPPF Awareness Program Manager) gave expert advice on what to expect. They've attended numerous conferences, so my mom and I were well prepared.

We arrived a day early to set up and familiarize ourselves with our surroundings. I was amazed at the variety of booths. I saw everything from dentures and toothpastes to dental chairs and medical missionaries.

One thing that stood out was that the IPPF was the only booth out of hundreds that dealt with an actual disease. This knowledge gave me a renewed energy and passion to spread awareness because it was clear we had our work cut out for us.

Our first day of the convention was educational to say the least. I quickly learned how to spot dentists, dental hygienists, and students among the throngs of people. My mom had a knack for drawing people in, and I was ready to share my personal diagnosis story. We had flyers and IPPF sunglasses to hand out. However, I noticed flyers and educational materials only went so far. The addition of sharing my patient experience helped reach many more inquisitive and

compassionate minds.

By the second day, I was eager to begin again. I noticed large groups of dental and dental hygiene students passing by, and I made a point to ask what school they were from and educate them on my disease. I was blessed to have two students from different schools stop by my booth to mention that they saw me present at their dental schools last year. They never forgot my story or my disease. I was encouraged to know that the IPPF's vision and efforts were coming to fruition. My mom and I also had the opportunity to talk in length to a dentist with 40 years of practice experience that hadn't had a pemphigus patient (or at least was unaware). This was not uncommon. Many dental providers had to be reminded about pemphigus and pemphigoid and may have only seen one or two patients in the history of their practice. One particular dentist visited the booth three times to talk with me about my disease, my treatments, and to bring his wife by to meet me so I could educate her as well.

We got many positive responses after taking the time to share my story. I'll never forget the dental hygienist who stopped by just to grab a pair of sunglasses. My mom asked her if she'd like to meet a patient with pemphigus and learn about the disease. She looked up surprised and then, eager to meet me, she listened intently. I watched as her eyes teared up while I relayed my story. She became emotionally connected to my pain, and I could see in her eyes a mirrored memory of a similar suffering. I didn't ever find out her story, but being open and vulnerable with people allows you to connect on a deeper level and leave a lasting impact.

The dental community was incredibly receptive of the IPPF Awareness Program. I realized that we have such a large audience and a perfect platform to move forward and educate them. I'm thankful for the opportunity to share my story in Florida. If anything, it helped me see firsthand the difference we are making as we connect with each individual. I saw their faces, I shook their hands, I answered their questions, I made contact. The convention was a powerful experience I look forward to being a part of again in the future.

Hannah Heinzig is a registered nurse and a pemphigus vulgaris patient. She travels around the United States presenting her story to medical professionals to raise pemphigus and pemphigoid awareness.



The Importance of Community

Janet Segall

Isolation was a common feeling for those who were diagnosed with pemphigus or pemphigoid (P/P) before the IPPF or the internet were around. This was why it was important for me to find others living with pemphigus vulgaris (the only disease I knew about at the time). Waiting 10 years after being diagnosed and feeling alone with this disease, I felt like it was the right time. Soon after I started the Foundation, the internet was evolving and people with pemphigus started contacting me. I had no idea how many people out there felt the same way I did.

The IPPF community not only provides information, but it gives hope. Knowing that there are people living and dealing with P/P who have achieved remission gives other patients hope. With that being said, the P/P community is important to the IPPF as well. Our community keeps the Foundation going through donations, volunteering, and (most importantly) sharing a special bond. Without your help to keep the Foundation running, information, doctor referrals, health coaches, educational seminars, and the Annual Patient Conference would not exist. We are all learning from each other. We need to continue to support the IPPF and our community.

Biggest Fan: A Daughter's Story

Sierrah Soto



It started when I was about 16 years old. What appeared to be blisters on his body started bothering my dad. At first they weren't noticeable. No one knew what they were from or why they started appearing. My dad assumed maybe it was an allergic reaction to our dog, but he soon found out that wasn't the case. As time went on, the lesions became more noticeable. They were on his face, head, and down his arms. No one was able to give him an answer about what the lesions were, how they started, and most importantly how to stop them. I began to wonder if I was going to lose my dad. It was very scary seeing the lesions take over and not knowing what was going on. We were all scared.

I have played soccer since I was three years old, and up until the lesions started, my dad never missed a game. Soon his appearance at my games, outings with the family, and even taking pictures had stopped. This was pretty hard on me. My parents have always been my biggest fans. At my games, my dad always yelled for me. He'd always let me know when I had a "man on" or when an opponent was coming. If I was in the perfect spot to receive a ball from my teammate he'd yell, "She's open, she's open!" It's difficult when your parents are so invested and supportive of you, and then one of those supporters stops attending games because of an illness. It was then that I realized how much the lesions were impacting my dad not only physically, but emotionally as well. It wasn't easy for him.

Years passed and he still didn't have any answers. He tried everything the doctors gave him, but the lesions remained—spreading and growing. When I was a senior in high school, my dad made appearances at my games, and he was there to walk down the field alongside, my mom, siblings, and me on my senior night. It was a wonderful feeling.

After high school, I committed to attend and play soccer at Western Virginia University Institute of Technology (WVU Tech). Living across the country was hard, especially when I couldn't be there to know what was going on with my dad. One day, I received a call that he had finally gotten an answer. Initially they thought it was one particular form of pemphigus, only to learn later that it was a different and less severe form. It was a relief to know that they knew what it was and they could start treating it.

so hard that I wondered if her eyes might get stuck and never close again. I remembered the amount of anger that instantly went through my body. I don't even think my dad realized what was happening. I truly realized how much I hated the lesions, how much I hated this disease called pemphigus.

No one was able to give him an answer about what the lesions were, how they started, and most importantly how to stop them. I began to wonder if I was going to lose my dad.

In 2012 when I was a sophomore in college and was hanging out in the dorm lobby with my teammates, I received a phone call from my parents. It was the phone call that I'd been waiting for. "They are going to start me on infusions that will help with my pemphigus," my dad said. Happy tears rolled down my face. The infusions were not fun for him, but they helped.

In May of 2015, my dad watched me walk across the stage and receive my bachelor's degree. In August of that same year, I started my soccer coaching career at WVU Tech. My dad is still one of my biggest supporters. In November of 2016, my dad achieved remission, and I again cried happy tears! I am now 24 years old and am so proud of my dad!

Coping with my dad's pemphigus hasn't always been easy; however, it has taught me about love and patience. To the family members and friends of pemphigus patients: We are their biggest supporters, and we must be strong for them! We are the bigger people when "the stares" lurk. Yes, we get angry, and we get sad. But most importantly, we celebrate the little steps forward. And that's how I coped.

Sierrah Soto was born and raised in Georgetown, TX, and currently lives in Beckley, WV. She earned her bachelor's degree in sport management and will soon complete her master's degree in athletic coaching education. Sierrah is in her third year as the Assistant Women's Soccer Coach at WVU Tech. Her hobbies include playing soccer, hiking with her dog-child Daisy, and working out.

We are their biggest supporters, and we must be strong for them!

My dad and I share a love for coffee, Starbucks in particular. One day when I was a freshman in college and home over Christmas break, we went to Starbucks. I remember this day like it was yesterday. It was the first time I experienced "the stares." While we were ordering and my dad was talking, a lady who was standing close to my dad was just staring at him. Staring at him



2017 PATIENT CONFERENCE

Report from Newport Beach

Becky Strong

Beyond the radiant sun, sand, and surf lies the sophisticated charm of Newport Beach, California. A place so intoxicating, one taste of the perfect life will keep you coming back for more. The 2017 International Pemphigus and Pemphigoid Foundation (IPPF) Annual Patient Conference was held at the Hyatt Regency Newport Beach, a resort-like hotel with fun activities, stunning landscapes, and three swimming pools. Attendees experienced sweeping views of the largest recreational harbor on the West Coast while getting to know others affected by pemphigus and pemphigoid (P/P).

Sergei Grando, MD, PhD, an immunodermatologist affiliated with UC Irvine Health who specializes in the treatment of P/P and Joel Laudenbach, DMD, Assistant Professor at Western University of Health Sciences School of Dentistry, were phenomenal cohosts. Both of these doctors have a strong history of helping the IPPF and our community, and we cannot thank them enough for hosting this conference.

The conference started on Friday afternoon with an introduction to pemphigus by Dr. Donna Culton from the University of North Carolina. Dr. Razzaque Ahmed from the Center for Blistering Diseases in Boston, Massachusetts, followed with an introduction to pemphigoid. Next, the IPPF hosted a town hall meeting where people gathered around tables to discuss various topics, such as IPPF communications, awareness and outreach, patient engagement, and advocacy efforts. We received a lot of great feedback about the future growth of the Foundation and great ideas for us to better serve our community.

Attendees were then invited to a welcome reception held on the tropical outdoor patio. Patients and their loved ones had the opportunity to mingle with doctors and IPPF staff in a casual environment. It was the perfect ending to the first day of the conference.

Saturday morning started bright and early with breakfast al fresco surrounded by palm trees and sunshine. Delicious food and fresh juices were perfect for

breakfast in paradise. It was a wonderful way to start the day of networking with fellow members and experts in our community.

After breakfast, IPPF Executive Director Marc Yale welcomed everyone to the conference and introduced Dr. Grando and Dr. Laudenbach. We then had the opportunity to hear from Kenny Metcalf. Kenny shared his story of living with pemphigus vulgaris (PV) and ultimately finding remission. I believe many of us are able to relate to the events and emotions Kenny shared. He was able to endure so much pain and suffering and come out victorious over PV.

Next, Dr. Laudenbach and Dr. Grando had a combined presentation that demonstrated the strength of having dermatologists and dentists manage a patient with P/P. The collaborative approach provides the best patient-centered outcomes. Dr. Peter Marinkovich of Stanford University spoke about topical skin and oral treatments, followed by Dr. Culton's presentation on steroids and immunosuppressants.

Dr. Aimee Payne from the University of Pennsylvania kicked off the next session with a presentation on rituximab therapy. Dr. Nancy Burkhart from Texas A&M University College of Dentistry followed by speaking about oral care for P/P patients. Dr. Burkhart even provided extra soft toothbrushes and dental picks/brushes for attendees. She also explained how each would be very helpful in our daily oral care routine. This session ended by a question-and-answer session by all of our morning presenters.

Lunch was served under large umbrellas outside. Attendees once again had the opportunity to network with each other and speak with leading P/P experts before heading inside for a group photo.

The afternoon sessions started with an Awareness Program update. IPPF Awareness Program Director Kate Frantz shared the wonderful news that the Awareness Campaign is now the permanent Awareness Program. The Awareness Program focuses on reducing diagnostic delays by educating dental professionals about P/P. These same dental professionals are often a P/P patient's first point of contact on the road to receiving a diagnosis. Kate also shared a new video made to promote the program.

Dr. Laudenbach and I joined Kate to give a real-life example of the effectiveness of the Patient Educator program. The program has been well-received at



Dr. Sergei Grando, Marc Yale, and Dr. Joel Laudenbach

dental schools around the country. Then Kate and IPPF Awareness Ambassador Coordinator Bryon Scott introduced the new Awareness Ambassador program to the community and issued the first Ambassador challenge.

The remainder of the afternoon was devoted to breakout workshop sessions. The first block of workshops included "The Importance of Patients Participating in Clinical Trials" with Dr. Animesh Sinha from the University at Buffalo, NY; "Women's Health and P/P" with Dr. Vanessa Holland of the University of California, Los Angeles; "Future Targeted Therapies" with Dr. Marinkovich; and "P/P Below the Belt" with Dr. Ahmed.

The second block of workshops included "IVIG Therapy" with Dr. Grando; "Mental Health and Chronic Disease" with Ivana Mitchell, a PV patient and Registered Social Worker and Psychotherapist from Toronto, Canada; "Insurance Issues" with Sabrina Yeamons, Patient Access Manager for Kroger Specialty Infusion. Dr. Burkhart and Dr. Laudenbach also led a question and answer session on oral care. Dental care products were available in this session as well.

The third block of workshops included "Caregiving" with Jack Light, Executive Director of the Family Caregiver Resource Center at St. Jude Medical Center. IPPF Peer Health Coach Mei Ling Moore led a session on "How to De-stress"; Ivana Mitchell repeated her session on "Mental Health and Chronic Disease"; and Dr. Holland shared her expertise in another presentation on "Women's Health with P/P."

After a long and educational day, attendees had an hour to catch their breath and don their best cocktail attire for an amazing evening of awards and



entertainment. The night started off with a cocktail hour, where guests were greeted by a bright photo booth. The awards dinner was a special time to recognize many people who have made a difference to patients with P/P over the past year. It was powerful to see all the people that have contributed to the Foundation's success.

The true highlight of the evening was the entertainment. Terry Lunceford from the Magic Castle in Los Angeles provided an amazing magic show with audience participation and big belly laughs from all. It was a fantastic way to start the show. His talents amazed everybody. Terry even shared some of the ways he performs his tricks, and we were still amazed.

Then Kenny Metcalf took the stage as Elton John. We all looked forward to Kenny's performance—especially after his powerful testimony in the morning—but none of us could have imagined the magic of the evening. Dressed as young Elton, from his jeweled hat down to his platform piano keyboard shoes, we were entertained by a man and his grand piano. It was awesome to see everyone smiling and singing along as Kenny performed Elton John's greatest hits. He also told us about the inspiration he received from many of the songs. People laughed, clapped, and sung along. Kenny even took requests. It was the perfect ending to a perfect day.

Breakfast on Sunday was once again served on the resort patio, and many people were still talking about the awards dinner and entertainment from the night before. After breakfast, Marc Yale welcomed everyone to the last day of the conference, and I started the morning off by discussing the importance of patients becoming self-advocates. IPPF Patient Educator Hannah Heinzig then shared how her experience with PV propelled her into legislative advocacy. After

hearing Hannah's presentation, many people were inspired to become advocates themselves.

Dr. Annette Czernik of Mount Sinai Dermatology in New York and IPPF Support Group Leader Esther Nelson led a discussion on doctors and patients working together, followed by a question-and-answer panel featuring the IPPF Peer Health Coaches.

After a short break, attendees reconvened to talk about research. Marc Yale gave an update on the IPPF's research initiatives, including the Natural History Study and the grants recently awarded to researchers by the Foundation. Dr. Grando shared research innovations happening in P/P, and Dr. Sinha spoke to the community about genetics. Dr. Payne addressed "Future Targeted Therapies in Pemphigus," and Dr. Ahmed addressed "Future Targeted Therapies in Pemphigoid." Dr. Czernik finished the session by discussing clinical trials and the importance of patient participation. Marc Yale ended the amazing weekend with closing comments.

This was a remarkable weekend. From disease basics and town hall discussions to inspiring presentations and world-class entertainment, this conference was surely one of the IPPF's best. We had beautiful weather in a tropical location with easy and direct access to the world's leading experts on our diseases. To top everything off, we had the chance to be together—the opportunity to know we are not alone and to meet and network with others who share in our struggle. We hope you had as much fun as we did, and if you didn't make it this year, we hope to see you in 2018!

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 Personal View



THE IPPF PATIENT CONFERENCE

Kenny Metcalf as Elton (Chris Gray Photography)

Fred Wish

I have to admit I'm in a loving relationship—with Southern California. So when the IPPF announced that this year's Annual Patient Conference was going to be held at the Hyatt Regency in Newport Beach, I was hooked. This year's conference marked the 20th year that the IPPF, with the support of sponsors and vendors, has brought patients, caregivers and medical professionals together to network, share information, and learn of new developments in research, advocacy, and treatment.

It was an impressive and heartwarming performance, but it took on a special significance to pemphigus and pemphigoid patients and caregivers, because Kenny is one of us.

This was my third IPPF conference, and one of the most satisfying. As it turns out, the great weather and setting were only part of what made for a memorable experience. When Kenny Metcalf, performer extraordinaire, walked onto the stage Saturday night, he stopped being the Kenny Metcalf many of us had chatted with during a day filled with workshops, meetings, and presentations. All of a sudden, Kenny wasn't Kenny. He

was Elton John sitting down at the piano. In voice, playing style, and gesture, he transformed himself into the rock icon and delivered hit after hit.

It was an impressive and heartwarming performance, but it took on a special significance to pemphigus and pemphigoid (P/P) patients and caregivers, because Kenny is one of us. On Saturday morning, he delivered a kickoff presentation, leading us through his well-documented struggle with pemphigus vulgaris (PV). It's a story that resonates with P/P patients who have battled this group of obstinate and unforgiving diseases: his long wait for a correct diagnosis, the effect on himself as well as his friends and family, the periods of despair, the joy derived from even small victories. Kenny's message of light at the end of the tunnel set exactly the right tone for the conference. His concert on Saturday evening was conclusive proof of the ability to triumph over adversity.

At this year's conference, I spoke with so many people whose stories parallel Kenny's, and, to a lesser degree, mine. My own battle with PV is not the point of this article so I won't detail it here except to say that I am currently in remission, having been free of lesions

and off medication for 21 months. There was one question I encountered in Newport Beach that I've been pondering ever since. At one point someone asked me what I was doing there. "You're in remission. If your doctor thinks your PV may have actually burned itself out, why do you keep coming to these gatherings?" In thinking about possible answers to that question, I've put together a list of reasons I'd like to share with you.

First, there is a sense of community at these conferences that you can't get from participating in the various P/P social media sites, although they are a valuable resource. To be able to meet face-to-face with fellow patients and form new friendships has been important to me in dealing with PV. I'm sure it's important to others as well. Being able to sit down in a relaxed setting to trade war stories or talk about everyday topics was one of the highlights of the conference.

Second, the information communicated by the subject matter experts, both in formal sessions and in casual conversation can be invaluable. Topics included strategies for coping with the stresses of living with a chronic disease, caregiver assistance, diet tips, medical research, and treatment options to take back to one's healthcare provider at home.

Third, it's no secret that the IPPF, for all the good work it's doing, remains a small organization that needs help to accomplish its mission. Attending the Patient Conference, especially this year with the expansion of local support groups and the full rollout of the Awareness Ambassador program, provides avenues for individual involvement that might not occur to people.

Last, and most important to me, even as someone in remission, is the sense that I want newly diagnosed people to have an easier time dealing with P/P than I did. This conference did a lot to spread the word. It is so easy to feel isolated in this battle. I left Newport Beach, after taking an extra day to explore the coastline and soak up some California culture, with a renewed awareness of what it means to be a part of something larger. Wherever and whenever next year's Patient Conference is, if it's possible for me to be there, I will.

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.

IPPF Awards Dinner

The IPPF hosts an Awards Dinner to honor those whose service to our community has made a significant impact over the previous year. It's a great opportunity for all those affected by pemphigus and pemphigoid to come together in celebration of each other.

Congratulations to our 2017 Award Winners:

LIFETIME ACHIEVEMENT AWARD

Dr. John Stanley

FOUNDER'S AWARD

Sonia Tramel

DOCTOR OF THE YEAR

Dr. Detlef Zillikens

DENTAL PROFESSIONALS OF THE YEAR

Dr. Nancy W. Burkhart & Dr. Terry Rees

STAR AWARD: OUTREACH

Carolyn Fota

STAR AWARD: PATIENT SUPPORT

Mei Ling Moore

Janet Segall

Jack Sherman

Rudy Soto

BRIGHT STAR AWARD

Kate Frantz

Miss the Patient Conference?

Download presentation slides at
www.pemphigus.org



Weathering the Storm

Jennifer Cavrudatz

Which storm am I referring to? Well, really there are two storms. This past September, Category 5 Hurricane Irma was forecasted to directly hit my hometown of Fort Lauderdale, FL. There was also the storm that I knew could brew inside of me, potentially causing a flare-up of my pemphigus. The storm inside of me was related to the stress of preparing for Hurricane Irma and the fear of what it could do to me, my family, and our homes. I had anxiety because I still wanted to travel to California for the IPPF Annual Patient Conference and for a scheduled appointment with Dr. Sergei Grando. I knew I had to protect myself from both of these pending storms.

First, let me tell you about the abbreviated version of my pemphigus journey, the storm within me. In the week between Christmas 2009 and New Year's Day, I experienced my first symptom, a horrible sore throat that felt like I was swallowing razor blades whenever I ate anything. I went to my primary care physician, and we tried antibiotics, antivirals, and antifungals to no avail. By this time, the inside of my cheeks, gums, and tongue were all involved. In February 2010, I was referred to an oral surgeon who said, "I think I know what this is." He proceeded to test for a Nikolsky Sign, which was positive, as the majority of the inside of my cheek came off and was now raw and bleeding. He said it was likely pemphigus or lichen planus, showed me some information from a dental textbook he had in his office, and advised that I would need a biopsy to confirm. My biopsy revealed paraneoplastic pemphigus (PNP). I also have a history of lymphoma. My next call was to my oncologist, who ordered a new PET scan. It thankfully confirmed I had no new occurrence and was still in remission from lymphoma.

I was one of the lucky few that was diagnosed within three months (or so I thought). I then started on prednisone. It took 100mg per day to begin to make a dent in my symptoms. Subsequently, various doctors have now questioned my original diagnosis, and I've been given at least five new potential diagnoses, including PNP, pemphigus vulgaris (PV), lupus, erythema multiforme, sero-negative (t-cell mediated) PNP, and most recently severe DIF-negative PV. My treatments have included high-dose prednisone, Cellcept, Imuran, Dapsone, & IVIG so far. My diagnoses include those by Dr. Anhalt and Dr. Grando, two of the most highly regarded doctors on oral blistering diseases. So, I am one of those hard to diagnose and treat patients. Despite all of this, I am doing much better with my current treatment, but I'm still hoping for the right combination to someday be in remission.

Now, back to that pesky Category 5 Hurricane Irma. I am a native South Floridian, so I am accustomed to hurricane drills. I went through Category 5 Hurricane Andrew, which passed to the south of my home, and Category 3 Hurricane Wilma, which was a more direct hit. This was different. Hurricane Irma, whose 185 mile-per-hour winds ended up lasting a record-setting 37 hours, was also one of the four strongest hurricanes

on record. Fort Lauderdale was clearly in its path. As stress is a major factor in pemphigus disease activity, I had to take steps to mitigate the damage that might occur not only from the hurricane, but also from the stress. The best way to do that was early preparation and having a great support system.

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For me, preparing early for the hurricane and making sure all the basic needs were covered helped keep my stress level down. Our house was already well prepared with hurricane windows and doors, high wind-rated roof shingles, and in-attic roof bracing. We made a list of all the supplies we needed and things that had to be done. We checked the list twice. We pulled out all of our hurricane supplies, which included the obvious things like flashlights, batteries, and a weather radio.

We filled up both of our cars with gas and had the propane company fill our underground propane tank—it usually heats the hot tub portion of our pool, but it's also used to power our generator. (Note to self: a dip in the hot tub during this time could have helped with relaxation, too.) Next, we got cash from the ATM. We began hearing about supplies running out at the stores and long gas lines. This only increased anxiety, so we tried to stop listening to the news and only watched new forecast updates. As anyone who lives in a hurricane-prone area knows, news coverage becomes singularly focused on storms like this. It's good to remember that the media is trying to stress the importance of making preparations for those who take a too relaxed approach.

Even with this in mind, I started getting anxious when there were reports of grocery stores running out of water and canned food on the news. Thankfully, my husband, my biggest supporter and champion, recognized this and immediately went to the grocery store and got plenty of canned food, bread, and a lot of water. He also went to Home Depot and got more supplies, such as batteries, rope, and propane for our gas grill. My family was also in contact with us. My brother, who lives in New York City, checked in with our mother, sister, and myself to make sure we were ok and had what

we needed. He offered his sofa bed if anyone wanted to leave and head north. I am so grateful for having such a supportive family around me.

Another necessary task was getting all of my prescription medications refilled early. I contacted my local pharmacy. They were able to override a few, but I had to contact my insurance company about some. I had to convince them to allow for an early refill due to Hurricane Irma and my plans to travel to California for my first IPPF Patient Conference. This was a big check mark off the “to do” list.

We will face many storms, some external and others internal. We always need to prepare for both.

When news reports were filled with images and reports of catastrophic damage in the Caribbean islands and we were under a hurricane watch, television coverage went into 24-hour news mode. These factors added to anxiety and stress levels, so we started more preparations. At this time, we had to bring all outside items indoors and secure them. It was approximately 95 degrees with Floridian humidity, so I lathered up with SPF 50+ sunblock. (I have found that almost any sun exposure causes some skin flare-ups for me.) All the patio chairs had to be moved into the dining room. All the orchids and other plants had to go into the laundry room. I now realize I have too many yard knick-knacks! After we finished, we swam in the pool to cool down and try to relax the mind and body some. Last, I did laundry in case we lost power and needed to pack for California. I also received a group email from our fabulous South Florida IPPF Support Group Leader, Nancy Corinella, reaching out to tell us to be safe and do what we needed to keep our stress levels down. Thank you to Nancy for being there for all of us.

We were as prepared as possible, so we waited for the storm. During the hurricane warning, the projected path of the storm’s center shifted so that it was right over us, to us being out of the “cone” completely, and then finally back in the cone, but not a direct hit. We contemplated evacuating further inland after seeing the destruction on the islands, but decided to stay home once it looked like we weren’t going to have a direct hit.

When the storm arrived and we lost power, I started

packing for the trip to California. This helped keep me busy and directed my focus and energy on something positive. I was really looking forward to the conference and hoped I wouldn’t have to cancel.

Once the hurricane passed, we were lucky to only have tree damage and no power. We worked on getting our house back in order. I reached out to Becky Strong and Marc Yale at the IPPF and let them know the airport was closed and wasn’t sure if I’d make it to the conference. They were very supportive and understanding. Luckily, the airport reopened and was back to normal operations the day before I was scheduled to leave. I made it to California and to my appointment that same day with Dr. Grando!

During the Annual Patient Conference, I got to meet Becky and Marc in person for the first time. I also got to meet many other patients, volunteers, doctors, speakers, and sponsors. It felt as if we’d known each other forever, even though we just met. The conference was full of information and positive attitudes. The Saturday night dinner and entertainment was also fabulous—special shout out to “Elton”!

Now I am back home and things are getting back to normal. There are still reminders of the storms. The streets are lined with debris that the city is trying to clean up. And although I tried to keep my stress levels down, I wasn’t as successful as I’d hoped. The storm within me manifested itself as a minor flare-up on my upper torso, but I’m managing it with clobetasol. I know it could have been much worse. I am looking forward to sharing the information I obtained at the conference with the South Florida Support Group at our next meeting and hope that it helps some of my fellow P/P patients and friends.

I guess the real take away here is life is going to happen. We will face many storms, some external and others internal. We always need to prepare for both. Remember to take care of yourself and do what you can to mitigate your stress. This will be different for each of us, but it is one of the biggest things you can do to help yourself. I hope you all stay safe and well during whatever storms you face.

Jennifer Cavrudatz has pemphigus and is currently on treatment of Cellcept and IVIG. She lives in South Florida with her husband Steve, and other close family nearby.



Pemphigus & Pemphigoid Patients Meeting

MUNICH, GERMANY

Rosa Maria Ober

The German Pemphigus and Pemphigoid Selbsthilfe e.V. was founded in 2010 in order to create a place for patients, family members, and friends to gain information on blistering skin diseases. The foundation operates independently and in all states of Germany with an annual conference at the UKSH University Hospital in Lübeck in the far north of Germany. The membership is free, and there are more than 180 registered members. The *German Pemphigus and Pemphigoid Selbsthilfe e.V.* became a member of the IPPF in 2017.

I've been a member of the group since 2015, as I've suffered from bullous pemphigoid since my early

childhood. I was diagnosed at 56 years old. I live near Munich, in southern Germany, and I decided very quickly to start a patient support group. I organized the first patient meeting in Munich in December of 2016. Our second meeting was held this past July. Twenty-two participants attended. As a trained nurse, I tried to find interesting and useful topics for patients, their families, and friends. The meeting included three sessions: steroid-induced osteoporosis therapy, psychology and autoimmune disorders, and dermatology research updates.

Over time I've realized that pemphigus and pemphigoid (P/P) patients rarely receive information or

advice on how to prevent osteoporosis during long-term steroid therapy. They are also rarely referred to a specialist. Many patients aren't asked if they take a vitamin D supplement or if they've had an osteoporosis check-up. Most of us are on long-term steroid therapy (longer than three months and more than five mg per day).

During the first session, Dr. Alexander Glogaza and Dr. Isa Feist-Pagenstert from LMU University Hospital in Munich, lead a discussion on osteoporosis and the possible increased risk of bone fractures. They explained how prednisone disturbs bone metabolism and that it impairs calcium absorption in the intestines. What can patients do about this increased risk? Each participant received a handout with a list of foods that are high in calcium, such as milk and milk products. Additionally, certain exercise such as walking, golf, and tennis may help reduce the risk of osteoporosis. *(Editor's note: This advice is in reference to preventing osteoporosis, only. For those who have already developed osteoporosis, weight-bearing exercises might risk bone fracture. As always, consult your doctor before starting any new exercise routine.)*

In cases of vitamin D deficiency, Dr. Glogaza and Dr. Feist-Pagenstert recommended taking a supplement. At the end of the session, attendees had the opportunity to have their questions answered by the doctors.

Many people affected with P/P report that stress may increase the occurrence of new flare-ups. This has happened to me as well. I asked a psychologist to talk on this topic. Dr. E. Noni Höfner, Diplom-Psychologin and

Head of the German Institute for Provocative Therapy DIP, introduced her work with Provocative Therapy, which was developed by Frank Farelly. Dr. Höfner showed us how to live with chronic diseases. She also humorously suggested there might be some advantages to having P/P, such as missing your mother-in-law's birthday party because your pemphigus may be severe.

During the third session, the discussion was lead by Dr. Mikós Sárdy, Associate Professor of Dermatology at Ludwig-Maximilian-University in Munich and Head of the Dermatology Department at Semmelweis-University in Budapest, Hungary. He conducts a lot of research on P/P and is highly experienced in the treatment of both. Dr. Sárdy explained how autoantibodies (AAB) destroy connecting proteins in different skin layers in both diseases and how different medications reduce the AABs. He stated that if therapy is interrupted, the AABs increase dramatically, and higher, or even new, immune suppressants may be needed to reduce the AABs again. Therefore, it's really important not to interrupt therapy due to side effects. Find a solution with your doctor!

Rosa Ober was born in 1959. She has had celiac disease since she was an infant and bullous pemphigoid since toddlerhood. Rosa is a trained general and obstetric nurse, and she has also worked as a pediatric nurse in the past. She was diagnosed with pemphigoid at the age of 56 and become a patient support group leader in 2015. She enjoys being a group leader because she knows both sides: healthcare provider and patient.

Have a Support Group?

LET US KNOW!

It doesn't have to be formal to be a group. All you need is another person, a place to sit, and time to talk. The important thing is to share your experiences and get the support you need. To find others in your area, contact Becky Strong: becky@pemphigus.org.

Find more Patient
Support Group
locations and dates
at pemphigus.org

IPPF 2016-2017 Volunteers

Thank you to all the volunteers who have supported the IPPF's mission of improving the quality of life for all those affected by pemphigus and pemphigoid.

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