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2015 $100K Challenge
International Pemphigus & Pemphigoid Foundation

www.pemphigus.org/100kchallenge

All qualifying dollars from donations made between April 24, 2015 and December 31, 2015 will be matched, up to $100,000. Donations must be "new money" (first time donor, or amounts over 2014's gift). Donations can be from individuals, businesses, or corporations, but cannot be for registrations, sponsorships, or sale of goods, tickets, or services.

What kind of donations do not qualify for the Challenge Grant?
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Donate online at www.pemphigus.org/donate
Hello pem-family! I hope this issue of the Quarterly finds you in good spirits and welcoming the Fall season. If you’re like me, you probably have a collection of quotes you pull out when the time is right. For me, I reflect on these thoughts and sayings often for inspiration, motivation, or reminiscing.

In his poem “Indian Summer,” William Cullen Bryant wrote: “Autumn ... the year’s last, loveliest smile.” As with a smile from a loved one, Autumn’s smile gives me reason to reminisce. So as I look back on 2015 and prepare for 2016, I ask each of you to reflect on your P/P journey and the role the IPPF played in it.

In this issue, IPPF Founder Janet Segall tells us why she started the IPPF (as the National Pemphigus Vulgaris Foundation) and the importance of supporting our programs and services (p. 4). Rudy Soto also tells us why he gives back to the IPPF (p. 9). Former IPPF President Dr. Badri Rengaragan interviewed Sally Okun from patientslikeme, an online community of rare disease patients offering support and supporting rare disease research (p. 10).

Make twice the impact!
Donate today and all eligible “new” money will be matched 100%.
Find out more or donate at www.pemphigus.org/100kchallenge

Almost daily we hear from a patient about their journey from first symptoms to diagnosis to treatment. In this issue, two patients share their stories on the lengthly, multiple doctor, misdiagnosis process and how the IPPF was there to support them. Thank you Elizabeth and Toni for sharing (p. 6 and p. 11). If you want to share your story, please contact Noelle Madsen at noelle@pemphigus.org.

Dr. Terry Wolinsky McDonald compares the seasons to the stages of P/P, flowing into one another, forcing patients to adapt (p. 7). Dr. Mirella Bucci writes about the current research on reactive oxygen species (ROS) molecules and the connection to BP blistering (p. 8). Put this all together and we have another fantastic issue of the Quarterly!

Lastly, Save the Date for the 2016 Patient Conference. The 2016 event will be held in Austin, TX, at the Hilton Garden Inn Downtown from September 22-24, 2016. The Conference Committee is working with our host, Dr. Terry Rees on the speaker list, agenda, and activities that will make this THE BEST CONFERENCE EVER! Registration will open in the Spring. Keep an eye out for more details as we finalize our plans.

If you’re in the Austin area and want to help out with planning or at the event, please contact Marc Yale (marc@pemphigus.org) or Noelle Madsen (noelle@pemphigus.org).

See y’all in Austin!

Questions? Comments?

If you have a question for the IPPF, want to comment on a previous article, or recognize someone in our community, contact us and we’ll get you an answer or response... and maybe use it in a future issue of the Quarterly!

www.pemphigus.org
Support the IPPF

Twenty-one years ago when I founded the IPPF, my main motivation was to find others in my area that had such a rare disease that I wouldn't feel so alone. The feeling of loneliness, where no one understands what you're experiencing can be devastatingly lonely. I remember thinking that I was going to die, and be alone since the prednisone cleared me up quickly and I looked on the surface to be normal again with no sores.

It was difficult in the early days of the foundation because there was no vast internet of information at my fingertips. Dr. Anhalt gave me his American Academy of Dermatology list of doctors so I sent letters (snail mail!) to all of the Dermatologists in Northern California hoping that they would tell their patients to contact me. Little by little I began getting some responses and calls. Once e-mail became more commonplace, even more people started contacting me. I realized how desperate people were to find answers and comfort. The Pemphigus Vulgaris Foundation, as the IPPF was originally called, was up and running. As time went by, people with P/P diseases wanted to connect.

In this technological era with the Internet giving us all the opportunity to search everything, and social media making it possible to connect with people around the globe, it is easier for people living with pemphigus and pemphigoid to connect to each other. When I was diagnosed in 1983, the only available drug for me was prednisone. There was nothing else available except gold and from what I knew about this drug, I did not want to take it. My local doctor agreed with me. With the advent of Rituxan and the other available drugs, some patients started clearing up or being stable very quickly, while others it took a bit longer – within a few years.

One interesting aspect about pemphigus and pemphigoid is that (except for CP) the diseases don't affect any of the body's internal workings. We don't feel sick. We can walk. We can work. We can go about our lives and basically forget about the disease. But, there is more to these diseases then meets the eye. That's where the IPPF comes in.

P/P patients and caregivers are finding each other on social media more quickly because of

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the IPPF. People world-wide are finding good credible information because of the IPPF. It can often still take months and months before someone can get a good diagnosis, especially if someone lives in an area where there is little knowledge about the diseases, but once they are diagnosed and find the IPPF, they have the best care and support at their fingertips.

The IPPF’s Awareness Campaign is currently focusing on dentists who are usually among the first to identify and begin treating these diseases. The more these specialists know about P/P, the quicker a diagnosis can be made.

The IPPF provides a forum for patients to ask questions of experts so that they get the best advice and information possible. The IPPF holds annual meetings so that new patients can hear and talk directly to the experts and to seasoned patients who know first-hand what they are dealing with. And, the IPPF does much more.

The IPPF helps patients get better. Period. When we’re well, few of us want to focus on what we have gone through. We want to just go on with our lives, move forward and see a clean bright future for ourselves. But, we have a gift too. Our gift is that we can pay it forward and help others with the same support we all had because of IPPF. Imagine a new person getting a diagnosis and there is no IPPF to provide the kind of support and information that we all had through our recovery.

It takes a lot of dedication to run a Foundation for a rare disease that most people don’t know or care about. The staff and volunteers of the IPPF are the most dedicated people I have ever met in bringing the support we all needed and the support that new people need. They deserve all our support whether financially or by volunteering that we can give them.

Despite the Internet, Facebook, and all the myriad ways we can connect, the IPPF brings order to the chaos of pemphigus and pemphigoid. It brings clarity. It brings together when we need it. Please send what you can afford to help them continue their work. Each dollar this year will be matched. These diseases are controllable but not curable so we all need the IPPF.

Pay it forward!! Please continue to support the IPPF.
DELAYED DIAGNOSIS:
Elizabeth’s Story
Patrick Dunn

For Elizabeth O’Connell, the journey to a pemphigus vulgaris (PV) diagnosis and correct treatment involved years of rotating doctors, side effects, and overwhelming anxiety about her ability to care for her son.

The blisters first appeared on Elizabeth’s face, body, and scalp in 2007. Three biopsies and a year later, she was told she had bullous pemphigoid. She was treated with oral, topical, and injected steroids, which caused advanced osteoporosis and hair loss. But Elizabeth’s blisters healed, and she was able to move on.

In the beginning of 2013, Elizabeth again became ill. This time, the symptoms started in her mouth. One dentist told her she had oral cancer. Elizabeth then saw a periodontist and received two gum grafts. Another physician implied that Elizabeth had had a mental breakdown and was somehow causing her own ears, nose, and eyes to bleed.

Over the next year, Elizabeth saw four different ENT doctors. They all suggested she was self-inflicting the wounds in her ears. Understandably, she began to lose faith in the medical community. She was exhausted from defending her sanity. “I was just so alone and defeated,” she said. “I didn’t have anyone in my corner.” As a single mother, Elizabeth worried about being able to care for her son. This was especially true as her symptoms progressed and compounded with stress and other medical issues. “My son is my world, and I hate that he saw me at the worst of the PV,” she said.

A fifth ENT was Elizabeth’s “miracle doctor.” He was shocked at how blocked her ears had become with dried blood. This blockage explained the loss of hearing and balance issues she was experiencing. This doctor knew about pemphigus vulgaris, and Elizabeth was finally given a correct diagnosis. “I just cried because I had found someone who could help and understand,” she said.

Like so many patients, Elizabeth’s diagnosis became a catalyst for learning everything she could about P/P. The name for her disease led her to Google, and Google led her to the IPPF website. Elizabeth participated in IPPF patient education calls and listened to the experiences of other patients. “Thanks to the IPPF, I let go of my constant fear and anxiety and learned to live and accept . . . my disease.”

Elizabeth’s ears still bleed, but she has a doctor she can trust. She has a new outlook on life. “Tasting your own blood for two years and brushing your teeth with a Q-tip is no way to live. I have peace and less anxiety.”

Elizabeth is also passionate about helping other patients avoid the kinds of complications she experienced. “I want desperately to help others with this disease and let them know they are not alone,” she said. “I can now, without hesitation, explain to a medical professional exactly what I have, and I have a list of all the current and proper medications.”

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Practicing Mindfulness

Terry Wolinsky McDonald, PhD

When I received a recent email about the fall IPPF newsletter, it coincided with my friends from “across the pond” visiting me in Pittsburgh, Pennsylvania. Because one of them is a renowned architect, we visited Frank Lloyd Wright’s Fallingwater masterpiece about one and a half hours from Pittsburgh. Although my friend had studied and admired the incredible house, he had never personally seen it before this trip.

Fallingwater was built in the 1930s as a country retreat for a very wealthy Pittsburgh family. The structure is cantilevered in a way that was not supposed to be structurally possible and with a waterfall running through the house itself that could only be seen or heard from the house’s many balconies. At the time it was being built, no one thought the house could be structurally sound. It was unlike anything being designed or built at the time. Its very uniqueness reminded me of people with pemphigus and pemphigoid and how unbelievable these disease processes are to most people.

The Fallingwater structure has not only withstood time and is still standing (with droves of visitors), but it has actually been nominated as one of the world’s great wonders. I think that those of us with rare diseases are, also, great wonders. If we had been ill with some of the P/P diseases in the 1930s, ’40s, ’50s and ’60s we would likely not even be alive – and yet here we are – alive – and, in many cases, thriving. We are living, walking, talking marvels who have beaten what were once considered unbeatable odds. This was unimaginable only decades ago, and more and more commonplace with every decade that passes. I choose to think of us as unique, beautiful, and amazingly strong.

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What About ROS?

Mirella Bucci, PhD

Research labs around the globe are working to determine the genetic basis of autoimmune mucocutaneous blistering diseases such as pemphigus vulgaris (PV) and bullous pemphigoid (BP). But, as with most diseases, this is a challenging task. This is partly because it is likely that no single gene is involved, but rather several genes are probably at fault.

To understand the mechanisms involved in these diseases, we need to identify the full set of mutated genes involved from the beginning of autoantibody formation to the death of skin cells. We then need to understand the interplay among all of these mutated genes along with the normal immune and skin cell components. Fortunately, some pieces are already in place. We know how normal cells function, how the immune system works when it is functioning well, and how cell death occurs. Research into the mechanisms of blistering diseases has identified some of the molecular players such as the autoantibodies and a role for certain compartments in cells (mitochondria) contributing to cell death.

In recent issues of *Experimental Dermatology* (doi: 10.1111/exd.12732) and *Journal of Autoimmunity* (doi: 10.1016/j.jaut.2015.05.004), research groups in the Netherlands and Germany, in collaboration with the German Autoimmune Blistering Diseases Genetic Study Group, tested the importance of two genes in determining susceptibility towards developing BP.

Using traditional genetic techniques, including DNA sequencing, they looked at the variation of mutations and copy number variations within the genes that encode for mitochondrial ATP synthase protein 8 (A6L) and Fc-receptors. A6L is a component of a multi-protein complex, complex V, which resides on mitochondria and is integral in generation of ATP, the energy currency that happens in these compartments. A6L was chosen for this study because these authors have previously shown that mutations in this gene can increase the severity in several animal models of autoimmune disorders, such as arthritis, and it does so by an increase in the levels of a highly reactive and generally highly damaging set of molecules called ROS (reactive oxygen species). ROS molecules have been shown to contribute to blister formation in BP patients. Fc-receptors

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(Fc-Rs), on the other hand, are more directly involved in autoimmunity because they reside on the surface of immune cells and recognize the autoantibodies that trigger dysfunction in the blistering diseases.

The first study of 308 German BP patients found one mutation within the gene for A6L was significantly linked to presentation of BP disease. Since mutations within this gene have been shown to increase ROS production, the authors surmised this could be happening in BP patients. More work is needed to show ROS molecules are formed at higher levels within BP patients and contributes to disease, but the data do suggest mutations within this gene is a risk factor for BP. As well, they provide more evidence to a therapeutic strategy that has been gaining some traction: targeting ROS as a therapy for blistering diseases.

The second study highlights the importance of ROS in BP, however, ROS molecules seem to be protective against disease. There are several variants (or alleles) of the Fc-R gene known to cause differing levels of ROS release by a set of immune cells called neutrophil granulocytes. In BP patients tested, the authors found an association between disease and Fc-R alleles leading to a decreased release of ROS. This was unexpected because ROS released by neutrophils have been implicated in dissolution of the junctions connecting skin cells that occurs in blistering diseases. More work is needed to determine how ROS may or may not affect disease progression and what the role of neutrophils is in mediating any damage by ROS.

Neutrophils are a presumed target of corticosteroids as a first line of treatment of BP and PV. It is important to discover other genes whose mutations and variations are linked to disease so a fuller picture of the molecular mechanisms can guide future therapies.

Mirella Bucci, PhD. is Secretary of the IPPF Board of Directors and a scientific journal editor living in San Mateo, California. She is a regular contributor to the Quarterly newsletter in the Research Highlights column.
An Interview with

Sally Okun
from patientslikeme®

As social media has grown in use and scope in recent years, several online communities and platforms have arisen for patients to share their experiences with each other. One such online platform is PatientsLikeMe, which was started by the brothers of a patient with amyotrophic lateral sclerosis (ALS). The idea was for patients to share their stories and guidance with each other in hopes of providing emotional support, care guidance, and generating hypotheses about effective treatment and care practices. Sally Okun, Vice President, Advocacy, Policy & Patient Safety at PatientsLikeMe, answers questions about the platform, use, and outcomes.

What is PatientsLikeMe and how is it different from the way patients currently interact?
PatientsLikeMe is a health information-sharing website for patients. It's the only place where people can share both personal stories and health data about their condition to help uncover ideas and new knowledge. Patients can learn from each other and find answers to questions on treatments, symptoms, and more. By sharing health data on our site, they're collaborating in real time with researchers and companies to improve the understanding of their disease and accelerate the development of new treatments. It's the kind of information sharing – or crowdsourcing – that can affect the lives of every patient and transform healthcare by putting patients at the center of the healthcare system.

How can a patient expect to benefit from joining PatientsLikeMe?
We have over 350,000 members sharing their experiences. That makes us one of the biggest and busiest patient networks. Members say the site helps them live better day to day because they see how they're doing, connect with others for information and support, and contribute to research.

What diseases are currently on PatientsLikeMe?
More than 2,500! We started ten years ago, focusing on chronic diseases and, specifically, neurodegenerative diseases. We spent the first few years building a platform that translated and improved the measures used in diseases like Amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), and Parkinson's. We wanted to bring what worked well to as many patient populations as possible and opened the site in 2011 to anyone with any disease. Today, our largest communities are in well-known conditions like fibromyalgia (with 60,000 members) and MS (with 40,000 members). We have many members with a range of rare diseases including Alkaptonuria (AKU), Idiopathic Pulmonary Fibrosis (IPF), and Mycosis Fungoides-type Cutaneous T-Cell Lymphoma (MF-CTCL).

Does the site have any skin diseases/conditions?
Absolutely. Psoriasis, eczema, and rosacea are well represented on PatientsLikeMe, as are various forms of melanoma. We have recently added some cutaneous t-cell lymphoma patients.

Does there have to be a pemphigus or pemphigoid section of the platform in order for pemphigus/pemphigoid patients to participate?
Any patient with any condition can sign up on PatientsLikeMe. While we're not trying to add every single condition known, we do have a wide range of conditions represented. This reflects our practice to listen to members and add specific conditions if they are needed but not yet listed. While the platform is open to all patients, we enable any group of patients to self-organize and combine

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My Road to PV Treatment

Toni Addy

My PV story began March 2014 and continues as of July 2015. What followed after March 2014 was a series of doctors, treatments, biopsies, and lab tests attempting to find the cause and appropriate treatment for my condition. It took five months for diagnosis and another month to locate a knowledgeable provider to establish the appropriate treatment protocol. I am hopeful that remission is in my near future.

It all began as I was turning 65 and beginning my retirement after 20 years as an RN in an acute care hospital in Central Florida. The accumulated stress of preparing for Christmas 2013, my December retirement, and the onslaught of oak pollen season in Florida in February caused my body to revolt.

I have memories of sitting at the computer and feeling a small fluid-filled blister under my tongue. It wasn’t painful and did not burst. Eventually, though, my mouth became a haven for inflammation with large white areas. Due to my oak pollen allergy, I also suffered head congestion and drainage followed by eye irritation with redness and itching. I was taking my generic Claritin® with minimal relief. In March 2014 I went to the clinic and was given nystatin, thinking oral thrush was upon me. With no improvement in a week, an ENT prescribed a course of mouth rinses, oral antibiotics, and, thankfully, prednisone for my inflammation. A biopsy of a lesion on the inside of my lower lip came back only as negative for squamous cell cancer.

Regrettably, I was not tested for pemphigus. The only things I could put in my mouth were liquids. Protein smoothies were my friend. I lost almost 20 pounds—which I could afford to lose, thank goodness! As I weaned off of prednisone (50mg), the oral irritations and erosions returned.

I was seeing a rheumatologist, who suggested I might have Behcet’s syndrome. We were getting close. In July 2014 I was up to 80mg of prednisone with oral improvement (able to eat roasted chicken!). My ENT attempted to wean me off with only oral rinses for support. My mouth took revenge and my extremities took notice with blisters on my back, arms, legs, groin, and chest.

I returned to the clinic. The doctor took one look at my mouth and body blisters, referred to her book, and said, “This looks like pemphigus vulgaris. I’m sending you to a dermatologist for a skin biopsy.” On August 6, 2014, the result came back positive for PV.

The clinic dermatologist treated my skin blisters with triamcinolone cream, oral tetracycline, and oral prednisone (40mg). Since she was not familiar with PV treatment, I was referred to the University of South Florida Medical School in Tampa. Unfortunately, it was a month out then the doctor cancelled because of a move to California! I was offered was an appointment two weeks after the original one with a third year resident. By that time I was becoming anxious, and my husband and I decided to do some work on our own. My husband found the IPPF.

I called the IPPF, and Noelle, continued on page 13
I owe my life to the IPPF. Without you guys, I would have never known what was actually going on with me and my body. Words cannot express my gratitude and gratefulness to all of you who have committed yourselves to helping people like me.”

Elizabeth’s story illustrates many of the reasons the IPPF Awareness Campaign was created. We too often hear from P/P patients whose delayed diagnoses have allowed for advanced progression of disease symptoms. The Awareness Campaign’s goal is to improve the quality of life of P/P patients through early diagnosis. Once diagnosed, the IPPF can arm patients with information about their diseases and connect them to broader resources. If you would like to help spread awareness of P/P, consider signing up to become an Awareness Ambassador by emailing ambassadors@pemphigus.org.

Patrick Dunn, MFA, is the Health Communications Specialist at the IPPF. He is a contributor to the Quarterly’s Awareness and You column. Patrick can be reached at patrick@pemphigus.org.

Rudy Soto is a pemphigus foliaceus patient and lives in Georgetown, Texas, with his wife and four children.
Talking About the Florida Support Group

This group is wonderful to get information pertaining to PV. It helps talking to others going through the same things as you are - Miriam

This group means I get different information and views on treatments, doctors and solutions for living with this disease - Nancy

We became much more informed. There are a lot of passionate people wanting to help - Rick

It’s good to know you are not alone with this disease - Joyce

I leave here more knowledgeable and relieved. Enjoy recognizing familiar faces and excited by the new faces. Amazed and humbled listening to the stories of other’s experiences. - Daphna

This meeting means so much to me. After years of feeling alone, I now know there are others with the same rare disease. The meetings are so informative, so helpful and so life changing. - Gigi

DO YOU HAVE A 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 be able to share your experiences and get the support you need.

If you want to find others in your area, contact Noelle Madsen at noelle@pemphigus.org.

...continued from MY ROAD, page 11

Madsen sent me a list of Central Florida doctors. Within two days Sand Lake Dermatology Center in Orlando contacted me with an appointment. The doctor confirmed the diagnosis of PV and was told to stay on prednisone (40mg). I was also prescribed CellCept® (1500mg).

As of July 2015 I am taking 3000mg of CellCept® and 10mg of prednisone daily. The blisters on my extremities are gone. My mouth is irritated with inner cheek erosions, small blisters under my tongue, a slightly swollen and tender tongue, and sticky saliva covering everything. I can eat soft, solid foods, taking small bites and chewing slowly. Eating at restaurants can be tricky. No fresh fruit, tomatoes, raw onion, or garlic. I can’t manage coffee or most common condiments.

My doctor suggested rituximab. I was approved for financial assistance from the drug maker. My first two infusions went well. I noticed slight improvement, mainly on my tongue. Chewing seems much easier. The sticky saliva seems reduced. I am maintaining an upbeat attitude to keep my immune system happy!

Hopefully my road back to health will continue without any traffic stops, and remission is in my very near future!

Toni Addy, BS, MA, AS, lives in Lakeland, Florida. is a PV patient, former school teacher, and retired RN. She wrote her story for herself and other PV patients and families.
their individual voices, we also pre-populate the site at times. We did this in 2011 when we were opening it up to all conditions and added about 300 conditions. About 20 patients report having pemphigus.

How do you decide what diseases you will add to the platform? We don't, our members do. Any patient with any condition can join PatientsLikeMe.

Can physicians utilize this platform, or is it only for use by patients? We're a platform for patients, but members can download the information in their profile to share with their doctors. Doctors can be patients too, and can use the site for their personal health and self-care management.

How do you control the quality of the information patients share? What if someone writes something that is not quite correct, or someone walks away with an unintended interpretation?

We have a team of clinicians who regularly review new information coming in about new diseases or medications. If they see something incorrect, they'll work with members to make sure they know how to add information accurately. And we regularly reassess to see if we can organize things differently to better capture information, and make modifications all the time. We also have a Community Team that moderates and regularly engages with patients in the forum. This team often provides support to members on how to best use the site for sharing information. It is important to note that we are not a medical site and do not provide medical advice.

Is the information a patient submits to the PatientsLikeMe platform public or private? Members are welcome to share as much or as little information as they're comfortable with on PatientsLikeMe. Some members set up their profiles to be public. That means that the information they share, including their user name, profile photo, demographic information including age, gender, location, and bio information in the “About Me” section is public, as are their reports on symptoms, treatments, and weight. For members who do not make their profiles public, their information is only visible to other members.

Does PatientsLikeMe sell any of the information patients contribute to the platform? PatientsLikeMe is a research-based platform built within a social network and freely available to patients. Our ultimate goal is to transform healthcare by including patient-generated data in the discovery and development process and to support outcomes that matter most to patients. To that end, the data that patients share about their conditions, symptoms and treatments in their profiles are de-identified and aggregated and shared with our partners to answer important questions of interest and help them develop better drugs, devices, equipment, insurance, and medical services. Revenue to support our work and the website comes from various sources including the pharmaceutical and biotechnology industry, academic and clinical research grants, and philanthropic organizations such as the Robert Wood Johnson Foundation (RWJF). We believe in transparency, and we tell our members exactly what we do (or do not do) with their data.

Is there any cost to join? Nope. It's free!

How does the PatientsLikeMe approach add to what the clinical and research communities do? While clinical and research communities have contributed significantly to the medical literature, they often do not have a systematic way of engaging healthcare's ultimate stakeholder — patients — in their own care. PatientsLikeMe is a scientifically oriented platform that enables patients to lend their voice to research. Together with our members, we have contributed to over 60 publications, many in prestigious peer-reviewed medical journals.

Is there a particular number of patients or amount of input needed to meaningfully help R&D efforts? This depends on the question and the condition. Our research team works with research partners and patients to understand the questions, how to best measure them, and jointly develop targets for the number of patients needed to participate or the amount of information that each member needs to contribute to draw meaningful conclusions.

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people versus diseased people. Sometimes people can see our suffering, but much of it is not apparent to the human eye.

I can only imagine the magnificence of Fallingwater in the fall, when all those beautiful, untouched trees’ leaves are so glorious as they change color and fall off the trees, in a representation of new beginnings.

As patients with special rare orphan diseases, we can consider the stages of our conditions as seasons, flowing into one another, forcing us to adapt. At the first symptoms and through diagnosis, many people face denial. Denial is, and always will be, the most-used defense mechanism humans have. It is extremely effective. Anger may follow, along with potentially depression and anxiety and finally acceptance.

As a psychologist with a special individualized approach for patients with chronic physical illnesses, I have been privileged to be on the journey with many people. The ages, genders, and educational and socioeconomic situations of the patients have not been good indicators of how well they will do in therapy and in coping with their “new normal.” Everyone’s emotional journey will be not be exactly the same, just as their physical journey will not be the same. There will be similarities along the way, and those whose diseases are in remission or more stable can definitely play very important roles in helping themselves and others who are struggling more.

My own journey has been as unique as anyone’s. Some days are more challenging than others. I have been fortunate to have supportive colleagues, most of whom still have no idea how my illnesses work or how they get triggered. If I need extra help I know whom to contact and when to contact them. If you find yourself having difficulties with denial, anger, depression, or other emotional issues, please do yourself a favor and find a professional to work with you and your own particular issues and support system.

As well, the IPPF and its Peer Health Coaches and immensely educational website and Annual Patient Meetings can be great resources as we navigate the seasons.

I know that when autumn arrives in Pennsylvania, I will be heading back to Fallingwater to see the wondrous site and its surroundings in that season. It will be a beautiful sight from many different angles, and I will have special memories to carry with me forever. I will continue to live my life and to make new memories, because that is my choice on my personal journey.

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

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Do you work with disease foundations and patient advocacy organizations? What type of work do you do with them?

We’ve worked with a broad range of nonprofits and advocacy groups. A list can be found at www.patientslikeme.com/about/partners. The nature of our collaboration varies from serving as a non-profit’s infrastructure for enrolling and managing member communications, to collaborating on research. It depends on the condition and the nonprofit.

How do you see the IPPF potentially working with PatientsLikeMe?

There are several ways to work together. Like our other rare diseases communities, we welcome patients to sign up, track their progress, connect with others, and contribute their information in a central place so others can learn from their experiences.

How can readers learn more about PatientsLikeMe?

Visit our website at patientslikeme.com and explore information our public Community pages or view member’s public profiles to see how health data is displayed in useful charts and graphs. Another source of information is our News page news.patientslikeme.com.

Badri Rengarajan, MD, is the former President of the IPPF Board of Directors and resides in northern California.
IPPF on Cafe Press

The IPPF CafePress store has shirts, sweatshirts, jewelry, bags, drinkware, and quite a bit more. There are three good reasons to shop at the IPPF CafePress store. First, when you use or wear these products, you raise P/P awareness. Second, you support the P/P community by purchasing items designed by others affected by P/P. Third, the IPPF receives 20 percent of the proceeds from each purchase.

Check out the IPPF web store at www.cafepress.com/ippf. There are always several holidays and other special days right around the corner.

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Donate online or download a mail-in form at www.pemphigus.org/donate