

AIMING FOR A CURE | REMEMBERING OUR HUMANITY | GETTING TO KNOW IMMUNE GLOBULIN

# Quarterly

Journal of the International Pemphigus & Pemphigoid Foundation



SUMMER 2020  
ISSUE #101

[PEMPHIGUS.ORG](http://PEMPHIGUS.ORG)

# SUMMER 2020



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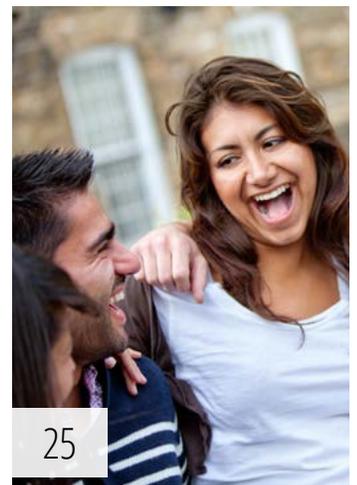
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## Message from the Executive Director

Summer is almost gone, and fall will be upon us soon. Many of us have children returning to school, whether it be in-person or virtually. All of us have been faced with challenges over the past six months, all different, but all challenges the same.

Although our lives have changed permanently with the global pandemic, we rise to these challenges. Like many of you, I remember the day I received the news that I had a rare, autoimmune blistering skin disease. I was unsure of what to expect, and I was scared. I knew that I had to face this thing head on, though I had to be realistic and manage my expectations. Just like that day 13 years ago, I must now put my health and welfare first, be mindful of others, show compassion when needed, remember to smile and laugh, and think positive. To do so, I rely on the strength of our community. Together, we can remain committed to improving the lives of all who are affected by pemphigus and pemphigoid.

In this edition of the *Quarterly*, you'll find stories about patients coping with the current pandemic. Some rely on themselves to show resilience, while others seek comfort in making small connections while social distancing. I know it may seem as if the world has come to a standstill. However, when you read about the IPPF's advocacy and disease awareness efforts, how immune globulin can help prevent inflammation and treat infection, or how the promise of T-cell therapy may someday produce a cure, I know you'll have hope!

Throughout this global crisis, the small staff at the IPPF has been committed to providing support. We launched virtual support group meetings, held weekly Patient Education webinars, and are busy planning our Virtual Patient Education Conference to be held from October 2-4. (Registration will open soon!) The IPPF also hosts a COVID-19 information page on our website and a community survey to learn about your current needs. We are also working with researchers to understand the emotional, psychological, and physical impacts that COVID-19 has had on our community.

Thank you all for your support during these trying times. As we move forward together, the IPPF will remain committed to our mission and will continue to provide hope for all those affected by pemphigus and pemphigoid.

Marc Yale  
IPPF Executive Director and MMP Patient  
[marc@pemphigus.org](mailto:marc@pemphigus.org)



*Cabaletta Bio co-founders Dr. Aimee Payne, Dr. Steven Nichtberger, and Dr. Michael Milone*

# Aiming for a Cure

## ENGINEERED T CELL THERAPY FOR MUCOSAL PEMPHIGUS VULGARIS

**David J. Chang, MD, MPH**

**“When I have a flare,** drinking water feels like drinking shards of glass.” This powerful statement, shared by a patient with pemphigus vulgaris (PV) involving the mouth at a recent IPPF Patient Education Conference, made a lasting impression on the Cabaletta Bio team. As we advance our lead drug candidate—one that is designed to provide complete and long-lasting remissions with a single dose for patients with mucosal pemphigus vulgaris—into the first clinical trials, we are constantly driven by our mission to develop and launch the first curative targeted cellular therapies for patients with autoimmune diseases. We are on the cutting edge of medicine: taking a patient’s own immune cells and arming those cells to fight their disease, thereby leading to a potential cure with a one-time treatment.

In a healthy immune system, antibodies are generated to seek out, selectively bind to, and eliminate

viruses, bacteria, and cancer cells based on “non-self” protein markers found on their surface. However, in patients with certain types of autoimmune diseases, these antibodies mistakenly perceive a part of the body as “non-self” rather than “self” and mount an immune response. These autoantibodies are produced by, and initially anchored to, the surface of B cells, which multiply and make more autoantibodies that eventually are released by the B cells to find and attack a patient’s own body, leading to disease.

PV is caused by an abnormal production of autoantibodies against proteins that are responsible for gluing together the cells of the skin and mucous membranes. In the mucosal type, which accounts for approximately 25% of PV and affects predominantly mucosal surfaces, the autoantibodies specifically target a protein called desmoglein-3 (DSG3). The autoantibodies disrupt the bridge-like connections of the DSG3 between cells,

leading to blister formation. Left untreated, mucosal pemphigus vulgaris may cause extensive blistering and erosions and may be fatal. However, in recent decades the condition has become more treatable with broadly immunosuppressive drugs, including corticosteroids and rituximab. While this approach often leads to transient relief of symptoms, it is not curative. Furthermore, these therapies often require re-treatment over a long period of time, which is associated with an increased risk of serious infections, other serious complications, and even death.

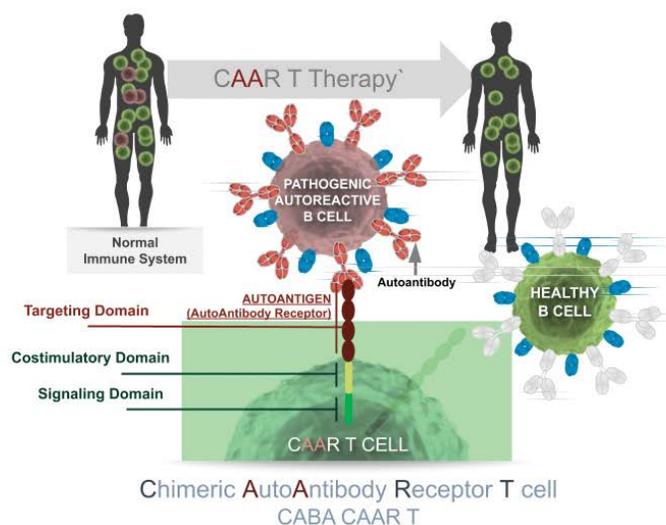
The Cabaletta Bio story began in the laboratory of Dr. Aimee Payne, a physician-scientist faculty member at the Perelman School of Medicine at the University of Pennsylvania. Dr. Payne has devoted her career to understanding the mechanisms and treatment of PV with the goal of developing a targeted, curative therapy for patients. Through cloning the B cell population from PV patients to understand why disease occurs, Dr. Payne’s research identified common features of the immune response among patients.

In parallel at the University of Pennsylvania, breakthrough efforts to apply engineered T cell therapies in refractory or relapsing B cell leukemias and lymphomas—diseases in which patients’ healthy B cells turn cancerous—were advancing through clinical trials. This

therapy involves removing some of the patients’ T cells and modifying them in a laboratory by adding a gene so that those T cells express an activating sequence and an antibody fragment. This redirects the patient’s T cells to activate and kill the B cells causing cancer. The genetically modified cells are then grown up into large numbers and reinfused back into the patient. Once in the body, the cells further expand and eliminate the cancerous B cells, but also the normal B cells. Dr. Michael Milone, a physician-scientist and transfusion medicine specialist who is also a faculty member at the Perelman School of Medicine, was a co-inventor and key driver of the preclinical discovery and translational efforts for this technology, which ultimately led to the first FDA-approved cell therapy for the treatment of B cell cancers.

With the hypothesis that a similar technology could be developed and adapted for B cell-mediated autoimmune diseases, Drs. Payne and Milone began a collaboration to assess the feasibility of a novel approach: developing Chimeric Autoantibody Receptor T cell, or CAAR T cell, therapy. The key insight was that in autoimmune diseases, displaying the protein targeted by autoantibodies on these CAAR T cells would drive them to home in on and kill only disease-causing B cells that express the autoantibodies on their

## CAAR T Graphic<sup>1</sup>



1. A CAAR T cell contains all or a part of the antigen as its targeting domain. The antigen is a protein (Desmoglein 3 in patients with mucosal pemphigus vulgaris) that recognizes the specific, disease-causing autoantibodies that are expressed on a limited number of B cells, which make up the antibody producing part of the body's immune system. The model CAAR T cell depicted here contains a signaling domain and a co-stimulatory domain that are designed to help the CAAR T cell recognize and eliminate the disease-causing B cells.

Cabaletta Bio<sup>®</sup>

## Research & Treatments

surface, while leaving the rest of the normal B cells of the immune system intact. CAAR T cells are a “living therapy” in that they can multiply when they see their target, expanding their forces to fight off the disease-causing B cells. Prior studies also suggested that a single infusion of similarly engineered T cells enables the generation of “memory” T cells that can persist for years, monitoring for and attacking any disease-causing B cells that may recur in the future. Therefore, CAAR T cell therapy is a target-specific, or precision, therapy that has the potential for long-lasting therapeutic effects in the absence of chronic immune suppressive therapy.

Recognizing the potential of this approach for mucosal pemphigus vulgaris, Drs. Payne and Milone, working with dermatology research fellow Dr. Christoph Ellebrecht, fused the target protein DSG3 to the signaling proteins that activate T cells, creating the DSG3 CAAR. The researchers infused diseased mice with the engineered DSG3 CAAR T cells, and their levels of DSG3-targeting B cells decreased, as did the occurrence of blisters. Furthermore, these engineered T cells were able to divide and multiply, supporting the hypothesis that this cell therapy could have long-lasting effects.

Based on this groundbreaking work supporting proof of concept for CAAR T cell therapy in mucosal pemphigus vulgaris and other B cell-mediated autoimmune diseases, Cabaletta Bio was founded in 2017 under the leadership of Dr. Steven Nichtberger along with Drs. Payne and Milone. Following the completion of a comprehensive preclinical testing program for our lead drug candidate, known as DSG3-CAART, Cabaletta Bio submitted an Investigational New Drug Application to the Federal Drug Administration (FDA) for permission

to start clinical trials for the first CAAR T cell therapy in patients with mucosal pemphigus vulgaris. The FDA provided the clearance in late 2019, paving the way for Cabaletta Bio to initiate a clinical study for its first drug candidate.

In January 2020, DSG3-CAART received orphan drug designation, a recognition by the FDA that the therapy is being developed to treat a rare disease. In May 2020, DSG3-CAART was also granted Fast Track designation by the FDA, which requires that the therapy meets the strict criteria of intending to treat serious or life-threatening conditions and to address unmet medical needs. This designation by the FDA further underscored the need for improved therapies for patients with mucosal PV that can provide reliable, complete, and long-lasting remission without the general immune suppression and B cell depletion caused by current treatment options. As an uncommon but much sought after recognition, Fast Track designation provides potential benefits to Cabaletta Bio, including the opportunity for more frequent meetings and interactions with the FDA during clinical development and the possibility of accelerated approval and/or priority review of the data generated from DSG3-CAART studies, which may aid in our efforts to provide an effective therapy to patients as soon as possible.

DesCAARTes™, the Phase 1 study sponsored by Cabaletta Bio that is designed to test the safety of DSG3-CAART in patients with mucosal pemphigus vulgaris, is actively recruiting patients who have active disease or disease exacerbations despite two prior or current standard therapies. We believe this is the first clinical trial of a cell therapy that is designed to specifically target only the disease-causing B cells in patients with an autoimmune disease. By harnessing the power of targeted cell therapy, DSG3-CAART has the potential to be a one-time curative therapy, or at least lead to complete and long-lasting remission off all other medications for patients with mucosal pemphigus vulgaris.

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*David J. Chang, MD, MPH, is the Chief Medical Officer at Cabaletta Bio and has over 20 years of experience developing drugs for autoimmune and immunoinflammatory diseases, most recently at AstraZeneca and GlaxoSmithKline. He received his medical training and education at Cornell University and New York University.*

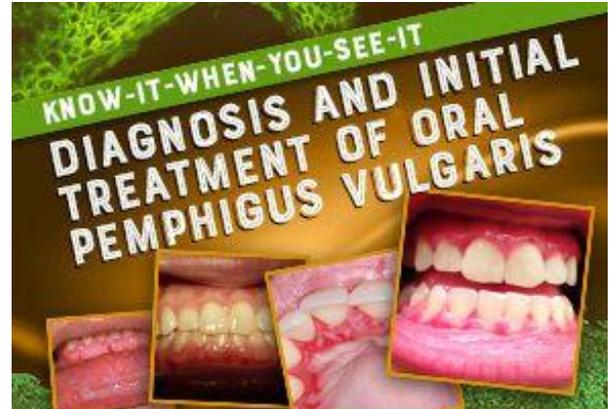
To learn more about the study, visit <https://cabalettabio.com/clinical-trials/>

To speak to someone about the study, phone: 800-711-4906 or email [cabalettatrials@iqvia.com](mailto:cabalettatrials@iqvia.com)

# CONTINUING EDUCATION COURSES



**This activity has been designed to address the educational needs of clinicians who diagnose and treat patients with pemphigus vulgaris (PV), including dermatologists, dentists, and rheumatologists. It may also benefit other clinicians who care for patients with PV.**



**This initiative has been designed to meet the educational needs of dental professionals who diagnose patients with pemphigus vulgaris (PV). It may also benefit other clinicians who care for patients with PV.**

**[www.pemphigus.org/student-and-continuing-education](http://www.pemphigus.org/student-and-continuing-education)**





Rare disease advocates gathered during Rare Disease Week on Capitol Hill 2020.

# COVID-19 Raises Urgency for FDA Rare Disease Center of Excellence

**Britta Dornan**

**I**n late February 2020, shortly before COVID-19 became our country's headlining healthcare concern, more than 900 rare disease advocates, including pemphigus and pemphigoid (P/P) patients, traveled to Washington, DC., to participate in Rare Disease Week on Capitol Hill. The event, hosted by the Rare Disease Legislative Advocates (RDLA), a program of the EveryLife Foundation for Rare Diseases, was designed to give rare disease advocates the opportunity to make their voices heard by members of Congress.

Among the policy issues that the army of advocates championed was the establishment of a Rare Disease Center of Excellence (COE) at the US Food and Drug Administration (FDA).

Advocates explained how the process of developing therapies for small patient populations presents unique challenges, which a COE would address. They maintained that a COE would not create new bureaucracy, but instead would remove communication barriers across FDA divisions and facilitate collaboration. They pointed out that the FDA already has authority under the 21st Century Cures Act (signed into law in 2016) to establish a COE. They further stressed that 93 percent of the 7,000 known rare diseases have no FDA-approved therapies, making improvements to our regulatory system an urgent need.

In the days, weeks, and months that followed Rare Disease Week, COVID-19 invaded our communities,

introducing new threats to an already vulnerable rare disease population. The 30 million Americans living with rare disease were told they may be at a higher risk for COVID-19 infection and its adverse health outcomes. The need for safe, effective, and affordable treatments for rare disease patients became even greater and more urgent.

Joined by their families and caregivers, rare disease patients must keep their voices raised in an insistent chorus until policies are changed and lives are saved.

Thanks to the chorus of disease voices that brought this issue to the forefront, a group of congressional members recognized the heightened need and took action. A bipartisan, bicameral group wrote to FDA Commissioner Stephen Hahn expressing support for the COE and requesting details on how a COE could be established. This letter was initiated by the co-chairs of the Rare Disease Congressional Caucus, including Senator Amy Klobuchar, Senator Roger Wicker, Representative G.K. Butterfield, and Representative Gus Bilirakis.

This congressional action would not have been accomplished without the persistence of rare disease advocates. However, the effort by the rare disease community to advance the COE and establish other essential policies is far from over.

Joined by their families and caregivers, rare disease patients must keep their voices raised in an insistent chorus until policies are changed and lives are saved. While in-person advocacy may currently be impeded, the EveryLife Foundation is employing virtual technology to empower advocates and continue their work. Through its Rare Across America program, advocates are meeting via Zoom with their members of Congress while they are in recess. Fast Forward for RARE offers personalized coaching to help prepare advocates for meetings. Young adult advocates are brushing up their skills with peer-led webinars through the Young Adult Advocates of RDLA (YARR) program. Advocates with

creative abilities are telling their stories through art and entering their pieces into the Rare Artist Contest via Facebook.

Information on these and many more opportunities to engage in advocacy is available at [EveryLifeFoundation.org](http://EveryLifeFoundation.org). Rare disease advocates should mark their calendars for Rare Disease Week on Capitol Hill 2021 taking place March 1st through March 4th. Applications for travel stipends will open this fall.

While Rare Disease Week may operate differently next year in this era of COVID-19, it will sound the same—with a harmony of determined rare disease voices leading the way toward progress.

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*Britta Dornan is a rare disease patient with primary lymphedema. She serves as the EveryLife Foundation for Rare Disease's Senior Director of Public Relations and Patient Engagement. Britta, her husband, and their two spoiled cats live in Arlington, Virginia.*



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<https://rarepatientvoice.com/ippf/>

# NORD Rare Action Network



## Kristen Angell

The National Organization for Rare Disorders (NORD), a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 280 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

The NORD Rare Action Network® (RAN) is the nation's leading rare disease advocacy network, working to improve the lives of over 25 million Americans impacted by rare disease. Its mission is to connect and empower a unified network of individuals and organizations with the tools, training, and resources to become effective advocates for rare diseases through national and state-based initiatives across the United States. The goal of RAN is to ensure that the rare disease community is represented and supported in all 50 states. RAN serves a broad spectrum of stakeholders, including patients and their families, caregivers, and friends; researchers; industry partners; physicians; and academics. While working on both the national and state level, RAN filters information to help address issues of national concern and engage rare communities to take action through policy, awareness, and educational initiatives in their state and local communities.

RAN members are led by volunteer state ambassador(s). Since its official launch in 2017, the state ambassador program now hosts 40 volunteer ambassadors spanning 36 states. State ambassadors help drive the efforts of the RAN in their state. State ambassadors are volunteers who are responsible for establishing and building a strong grassroots advocacy network of rare

disease advocates within their state to increase awareness of rare diseases and the challenges patients and their families face. State ambassadors serve as official liaisons between NORD, their state networks, government agencies, and elected officials working toward improving the quality of life of patients and their families.

Due to the recent COVID-19 pandemic, NORD's RAN volunteer ambassadors have been hosting virtual rare discussion groups. These group discussions enable the rare disease community to come together during this difficult and unprecedented time. These groups have allowed us to exchange stories and experiences with respect to the impact of the COVID-19 pandemic on the lives of those living with rare diseases. Attendees are able to share, ask questions, and receive updates from NORD. Discussion topics have included how the pandemic has affected rare disease treatment, medication access, and access to telemedicine. In addition to addressing topics of concern, RAN volunteer ambassadors will regularly host these virtual discussion groups through the remainder of 2020. These meetings are open to everyone. Please join us and check back regularly as more meetings are added daily. Alone we are rare, together we are strong.

For more information and to become a part of RAN today, visit: <https://rareaction.org> or contact [action@rarediseases.org](mailto:action@rarediseases.org).

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*Kristen Angell is the Associate Director of Advocacy at the National Organization for Rare Disorders (NORD). Kristen oversees the Rare Action Network program at NORD, a grassroots based advocacy network for all rare disease stakeholders.*

# Regeneron & Sanofi Genzyme Join IPPF Corporate Council

Join us in welcoming our newest members of the IPPF Corporate Council, Regeneron & Sanofi Genzyme. At the beginning of 2020, the IPPF launched the Corporate Council as a collection of top stakeholders that are committed to facilitating collaboration and information exchange among patients, the IPPF, key opinion leaders, health-related organizations, and industry. We believe that only through an open and cooperative collaboration among all stakeholders will we effectively be able to address issues facing the pemphigus and pemphigoid (P/P) community.

The IPPF Corporate Council focuses on three areas of emphasis: access, advocacy, and awareness. Within these focus areas, the IPPF Corporate Council develops and supports activities and programs that ensure the IPPF fulfills its mission of improving the quality of life for all people affected by P/P through early diagnosis and support.

Membership in the IPPF Corporate Council demonstrates an organization's leadership and commitment to addressing the challenges facing our patients. Involvement in the Council also provides the IPPF with an extended network of expertise and insight to ensure that we continue to address the unmet needs of all patients.

Please join us in welcoming our newest members  
to the 2020 IPPF Corporate Council



Thank you to the  
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and the  
UNGER FAMILY

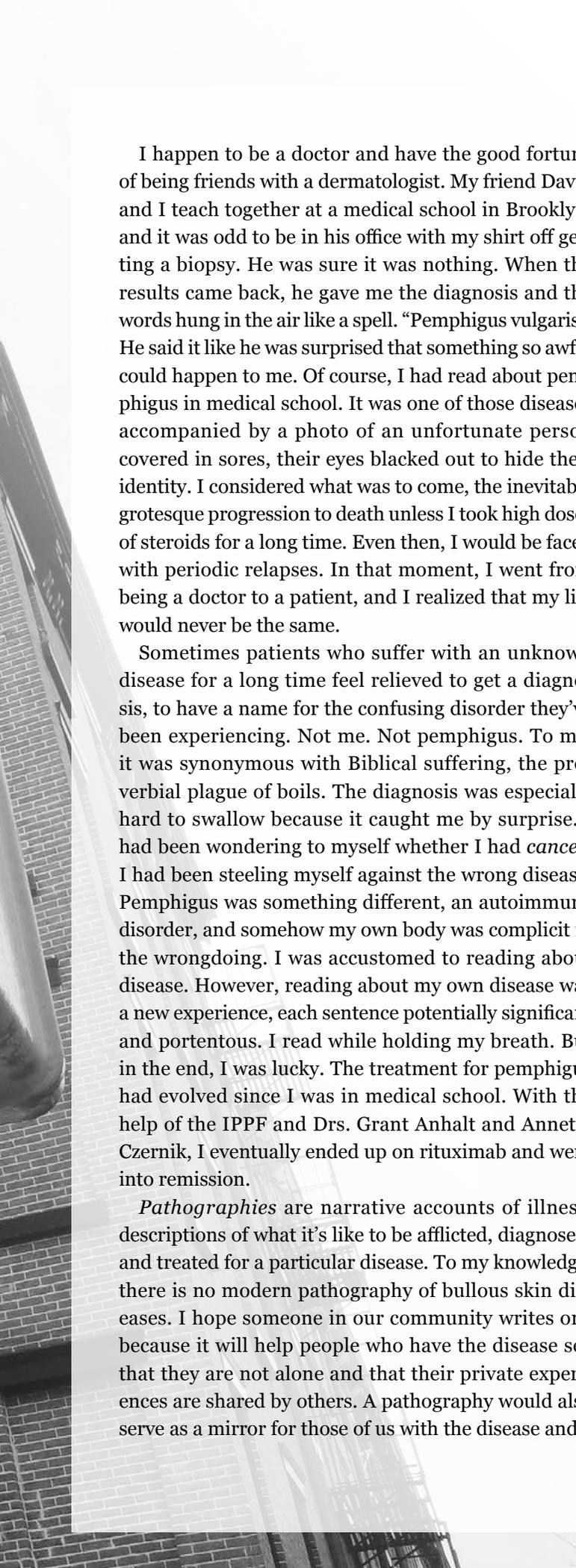
For their continued support of the IPPF Awareness Program

# Remembering Our Humanity

A DOCTOR'S OWN PV DIAGNOSIS PROVIDES PERSPECTIVE  
DURING THE COVID OUTBREAK IN NEW YORK

**Mert Eroglu, MD**

**L**ike many patients with pemphigus, my journey of experiencing symptoms, being diagnosed, and receiving treatment was one of anxiety and uncertainty. I remember sitting with my wife around the time of my initial symptoms. We were just starting our lives together, our first child had been born, and we had bought a house. I had a spot of skin on my chest that mulishly refused to heal. I put every manner of cream and ointment on it, I took vitamins and collagen supplements, and bought an aloe vera plant. Then another spot appeared on the side of my nose. It took me awhile to connect the dots and to realize they might be the same problem. And so, the disease did not come as a lightning bolt that changed my life overnight, but rather something insidious and unrelenting that slowly dawned on me, a gradual realization rather than a sudden revelation. Eventually I was covered with lesions and getting blood tests and biopsies.



I happen to be a doctor and have the good fortune of being friends with a dermatologist. My friend David and I teach together at a medical school in Brooklyn, and it was odd to be in his office with my shirt off getting a biopsy. He was sure it was nothing. When the results came back, he gave me the diagnosis and the words hung in the air like a spell. “Pemphigus vulgaris.” He said it like he was surprised that something so awful could happen to me. Of course, I had read about pemphigus in medical school. It was one of those diseases accompanied by a photo of an unfortunate person covered in sores, their eyes blacked out to hide their identity. I considered what was to come, the inevitable grotesque progression to death unless I took high doses of steroids for a long time. Even then, I would be faced with periodic relapses. In that moment, I went from being a doctor to a patient, and I realized that my life would never be the same.

Sometimes patients who suffer with an unknown disease for a long time feel relieved to get a diagnosis, to have a name for the confusing disorder they’ve been experiencing. Not me. Not pemphigus. To me, it was synonymous with Biblical suffering, the proverbial plague of boils. The diagnosis was especially hard to swallow because it caught me by surprise. I had been wondering to myself whether I had *cancer*. I had been steeling myself against the wrong disease. Pemphigus was something different, an autoimmune disorder, and somehow my own body was complicit in the wrongdoing. I was accustomed to reading about disease. However, reading about my own disease was a new experience, each sentence potentially significant and portentous. I read while holding my breath. But in the end, I was lucky. The treatment for pemphigus had evolved since I was in medical school. With the help of the IPPF and Drs. Grant Anhalt and Annette Czernik, I eventually ended up on rituximab and went into remission.

*Pathographies* are narrative accounts of illness, descriptions of what it’s like to be afflicted, diagnosed, and treated for a particular disease. To my knowledge, there is no modern pathography of bullous skin diseases. I hope someone in our community writes one because it will help people who have the disease see that they are not alone and that their private experiences are shared by others. A pathography would also serve as a mirror for those of us with the disease and a

template to guide patients through the different stages of management. It would also help to communicate with others about what it’s like to live with the illness, an experience that extends beyond the patient’s body to immediate family, friends, and acquaintances.

A common theme in pathographies is that somehow the disease, as terrible and burdensome as it may be, ends up paradoxically being a blessing. The illness opens a window and provides an insight into life that was not available during the time of health. When I was diagnosed, I felt plunged into a new reality, one that felt so newly authentic that reality itself was redefined. It made me feel that the coherence of my daily life was an illusion, and that under the surface there was a radical vulnerability. *How could this experience not lead to a deepening of my identity? How could I not be transformed?* I think anyone who gets a diagnosis, this new experience of living with danger, can only feel more connected to the gift of life and to everyone around them. So yes, the disease has paradoxically been a stroke of luck for me. I can say this partly because I am in remission. I might not feel the same way if I were taking heavy doses of steroids for a long time.

Part of the modern experience of illness is to Google it. For better or for worse, you learn about your disease on websites and on social media, where we also meet other travelers who can shed light on where we have been and what is in store for us. In this way, I met a new family—the online global community of people with blistering diseases. (We need to do more to support this informal community that is often the first line of contact for the new patient). I felt compelled to get involved with the IPPF and to try to be of help in whatever way I could. I feel very fortunate that due to the efforts of patients and generous donors like the Sy Syms Foundation, the IPPF exists as a haven and a resource for people around the world with bullous diseases. Going to the annual patient conference has been one of the most galvanizing experiences of my life, and I would recommend it to everyone who has the time and the means to do so.

I continue to practice medicine, and the disease has made me a better doctor. Part of the struggle of a young doctor is grappling with the suffering of others. You mean well, you have empathy, but the application of that empathy causes you pain. So there is a natural resistance in dealing with the difficult and insoluble

problems of your patients. Having your own disease broadens your perspective, it erases some boundaries between the doctor and patient, and makes it easier for the doctor to be steady and present with a patient. Not to mention, it's possible to understand what someone is going through when they're sick and afraid.

During the COVID-19 surge in Brooklyn, NY, I worked in one of the emergency departments that was hardest hit, and our entire hospital turned into a COVID-19 treatment facility. We converted every available auditorium and office space to the service of patient care and had, at the peak, three freezer trucks outside for the dead. The patients were terrified, and they were dying, particularly the elderly and those with immunodeficiencies. I thought of the few patients with blistering diseases that I had cared for in our ER and hoped they were safe and sheltering in place. Our healthcare teams were struggling with our own issues: the lack of adequate personal protective equipment, the fear of contracting the disease, the long work hours. We were worried about bringing the disease home to our families. The hospital and emergency room were full. We had spilled out into tents on the street and were struggling with the crushing burden of disease and a simultaneous lack of resources.

In this setting that felt a little out of control, we decided that family members were not permitted in the ER. There was the fear of contagion from the sick patients and it was simply too busy. Many patients spent hours and days in the emergency department alone, breathless, worried that they were going to die, and surrounded by strangers in masks and gowns. Many people died alone. Without family members there and patients that were too sick to talk, the emergency department became oddly quiet, like a laboratory. In this environment it was easy to feel like a technician, adjusting ventilator settings, checking lab values, and spending much of the time at the computer away from the potentially contagious patients.

At one point, I was taking care of a 100-year-old Hasidic woman with COVID pneumonia. I was desperate to send her home so she wouldn't die in the hospital, but her blood pressure dropped and we had to keep her. Her son kept calling me to find out how she was doing, and I finally told him, "She's 100 years old with pneumonia in both lungs. She's not good.

She's not going to do well." When he asked to talk to her, I told him I was too busy. He called me back ten minutes later and I told him that his mother was no longer conscious. He told me that it was okay, but that it was very important for him to recite a prayer for her

## *How could this experience not lead to a deepening of my identity? How could I not be transformed?*

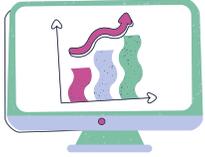
and asked me to hold the speaker to her ear. At the time, I had ten other pressing things I needed to do. Medically, each one of them was more important than this phone call. But I stopped what I was doing out of respect for this 100-year-old woman, and I put the cell on speakerphone for him to talk. He started the prayer of the dead, began to cry, and was barely able to get the words out. I then noticed she had numbers tattooed on her arm. He was crying for his mother and praying the Shema, the verses of unity, and it woke up an emotion in me that I had forgotten about. I remembered the moment of despair when I received my own diagnosis, a moment that I carry with me always, one that has become a part of me. I remembered that I was there to do the human task of doctoring, of providing comfort. I remembered how precarious it is to be alive and healthy and felt something akin to humility mingled with gratitude. Time slowed down, and I felt restored to myself. When the man on the phone was done with his prayer, he thanked and blessed me, and I thanked him in return.

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*Mert Erogul, MD, is an emergency physician at Maimonides Medical Center in Brooklyn, NY, and an Assistant Professor of Emergency Medicine at SUNY Downstate School of Medicine. He was diagnosed with pemphigus vulgaris in 2012 and is currently in remission.*

# IPPF PATIENT SERVICES

2020



## PATIENT EDUCATION WEBINARS

Feature leading P/P physicians and scientists. **We've held 17 webinars this year** in response to the COVID-19 pandemic. Recordings of past webinars are available on the IPPF website.



## FIND A DOCTOR MAP

Provides patients with contact information for medical and/or dental professionals familiar with P/P. The map has been **accessed over 1,100 times this year**.



## PATIENT SUPPORT GROUPS

The IPPF website includes a list of U.S. and International support groups and organizations. The **South Florida, Mid-Atlantic, and Tri-State NY groups held virtual meetings this summer**.



## PEER HEALTH COACH PROGRAM

P/P patients that are specially trained and help **reduce patient anxiety and uncertainty**, while providing unbiased disease and treatment knowledge.



## WWW.PEMPHIGUS.ORG

Visit the IPPF website to access these **free patient services**, as well as information about P/P diagnosis, treatment options, research initiatives, and clinical trials.

# Getting to Know Immune Globulin

Michelle Vogel, MPA, & Linda Kobert, RN, MSN

**I**mmune globulin (Ig) is a sterile solution containing human antibodies. It is prepared from plasma collected from thousands of donors and is used to treat inflammation and prevent infection. It can be administered through a vein (intravenously or IV) or under the skin (subcutaneously or SC). It takes approximately 250 plasma donations to treat one patient with pemphigus or pemphigoid (P/P) for one year.

Different manufacturers produce different brands of immune globulin, but every brand relies on plasma collected from specialized plasma donation centers. Donations made at hospitals or through the American Red Cross are not used to produce Ig and other plasma protein therapies.

## Are we in danger of a shortage?

The simple answer is yes. In 2019, many sites of care (hospital outpatient infusion centers, physician infusion suites, and home infusions) reported having problems getting access to certain brands of Ig. Policies were enacted to ration Ig use, with priority given to primary immunodeficiency patients and transplant patients.

The Ig supply is currently recovering from the 2019 shortage, but a new threat due to the COVID-19 pandemic is now affecting this recovery and could lead to another shortage. When COVID-19 social distancing restrictions were enacted, people stopped donating plasma because they were staying home. As a result, according to industry experts, plasma donations in the United States are down more than 30 percent in recent months. Even as the country reopens, plasma donations have not returned to the levels needed to prevent a serious shortage of Ig by the end of this year.

Past Ig shortages were a result of many things, including regulatory problems, issues with manufacturing, reimbursement challenges, and distribution obstacles. However, the current situation is simply the result of a lack of plasma. We can prevent this shortage

from happening, but we need to work together to increase the plasma supply.

## What is the donation process like?

The plasma donation process begins with healthy volunteers who must meet strict health requirements. Detailed questionnaires, a physical examination, and a blood test are administered to identify any factors that may make the donor ineligible. These extensive safety measures are designed to protect both donors and plasma product recipients and to ensure the safety of all plasma protein therapies.

The donation process involves a procedure called plasmapheresis in which whole blood is removed through a needle in the arm. The blood is pumped through a machine that filters out the red blood cells and platelets and returns these to the donor, reserving the plasma.

An individual's body replenishes its plasma supply within 24 to 48 hours, so those who donate plasma can give up to twice a week. (Blood can only be donated once every 56 days, because it takes much longer to replenish red blood cells.)

All initial donations are placed on hold until the donor returns to provide a second donation within six months. If the donor does not return, that initial donation is discarded. The second and subsequent donations allow for additional health screenings and testing. Subsequent donations also demonstrate the donor's ongoing commitment to plasma donation, which is important to maintain the supply.

All plasma donations are held for 60 days after collection. During this period, samples are tested at several stages for viruses. The testing methods can detect levels of viruses—including COVID-19—at an early stage, even before a person has developed symptoms. Over the years, this technology has dramatically improved the quality and safety of the plasma supply.



## What is the manufacturing process like?

The manufacturing process is an intricate series of steps, each ensuring the quality, purity, and safety of the plasma therapies produced. On average, it takes seven to 12 months to manufacture plasma-derived products from the time of donation to the finished product. The FDA licenses and routinely inspects plasma donation facilities. In addition, the Plasma Protein Therapeutics Association establishes internationally accepted standards that exceed regulatory standards of safety.

When manufacturing begins, individual plasma units are pooled with thousands of other individual units. In the case of Ig therapy, the pooling of plasma allows for patients to receive a wide variety of antibodies with each infusion.

Different types of plasma proteins are separated during a process called fractionation. Once separated, plasma proteins go through a rigorous series of steps to filter and inactivate any infectious material that may remain. After a final filtration process, the product is bottled and ready to ship.

## Is it safe to donate at plasma donation centers during the COVID-19 pandemic?

The Department of Homeland Security considers plasma donation centers and their workers a “critical infrastructure industry,” which means plasma donation centers are open and accepting donations. Plasma donation centers follow rigorous federal, state, and industry safety standards, including social distancing.

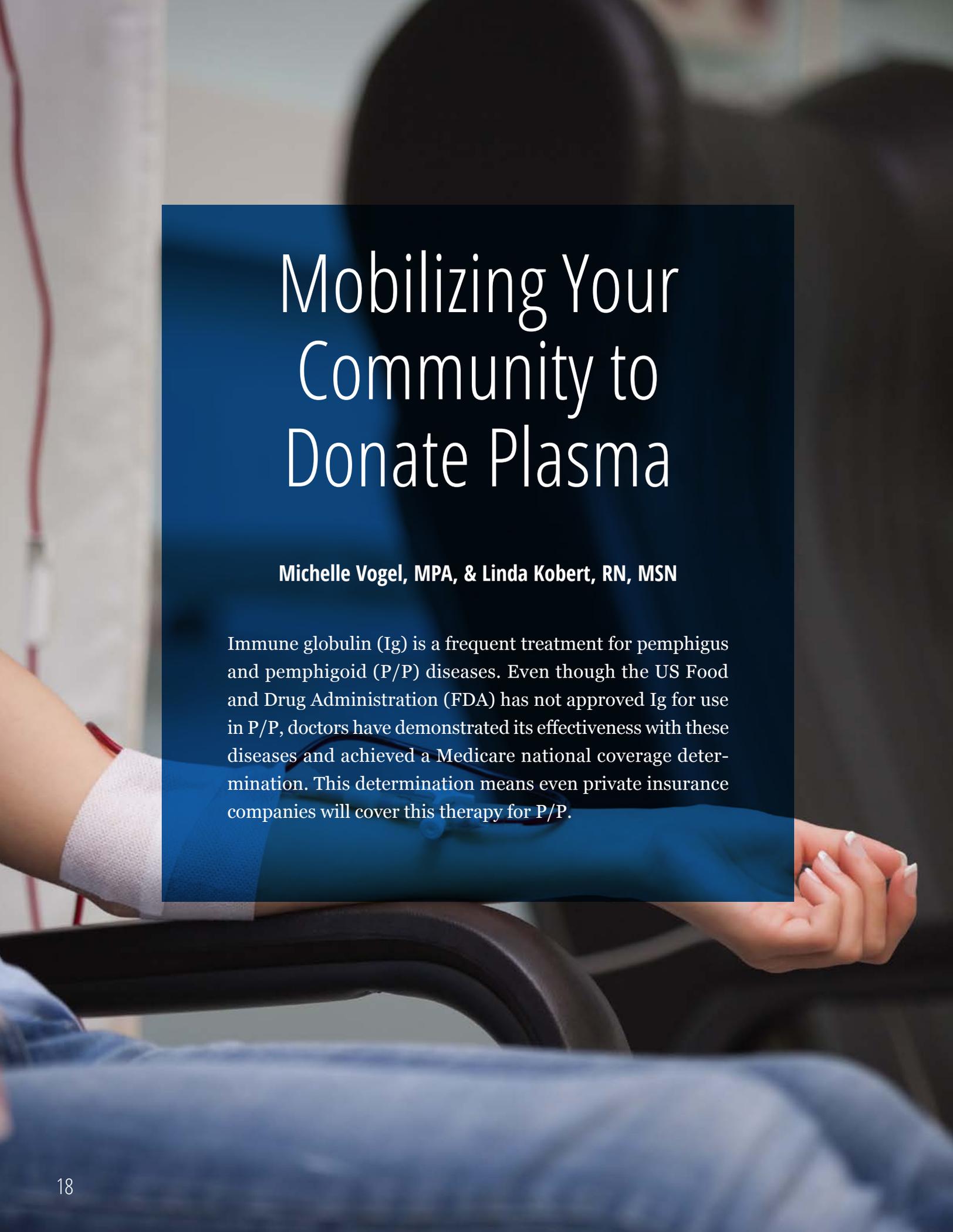
Those who plan to donate should call ahead to make an appointment at your plasma donation center. Ask about safety measures in place for COVID-19 infection prevention, and bring a face mask to wear during the donation process.

Donation centers are located throughout the US, but donors must choose one within a 60-mile radius of their home address and donate at that center only. To find one near you, visit [www.donatingplasma.org](http://www.donatingplasma.org).

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*Michelle Vogel, MPA enjoys helping rare disease patients find a "voice" in our complex healthcare system. She is honored to be the person to assist patients in navigating their healthcare, finding affordable health insurance, ensuring their lifesaving therapies are affordable and accessible, and making sure they don't fall through the cracks. She is the Vice President of Patient Advocacy and Provider Relations at CSI Pharmacy.*

*Linda Kobert, RN, MSN, has a passion for breaking down the complex language of medicine to help rare disease patients and their families better understand how to manage their disease and the healthcare system. She is the Director of Patient and Provider Relations at CSI Pharmacy.*

A photograph of a person's arm with a white blood pressure cuff. A hand is being held by a healthcare professional. The background is blurred, showing a person in a white coat.

# Mobilizing Your Community to Donate Plasma

**Michelle Vogel, MPA, & Linda Kobert, RN, MSN**

Immune globulin (Ig) is a frequent treatment for pemphigus and pemphigoid (P/P) diseases. Even though the US Food and Drug Administration (FDA) has not approved Ig for use in P/P, doctors have demonstrated its effectiveness with these diseases and achieved a Medicare national coverage determination. This determination means even private insurance companies will cover this therapy for P/P.

Immune globulin therapy is especially important now during the global coronavirus pandemic because, unlike other medications, Ig does not suppress the immune system. Some physicians are switching patients from immune-suppressing treatments like rituximab to Ig, since a suppressed immune system is a risk factor for developing a more severe case of COVID-19.

Ig is not a drug that can be mixed up on demand in a laboratory. It is made from donated human plasma, the golden-colored liquid portion of whole blood that remains after the red blood cells are removed. Pharmaceutical companies use proteins found in the plasma to create products such as Ig that can safely treat a variety of diseases.

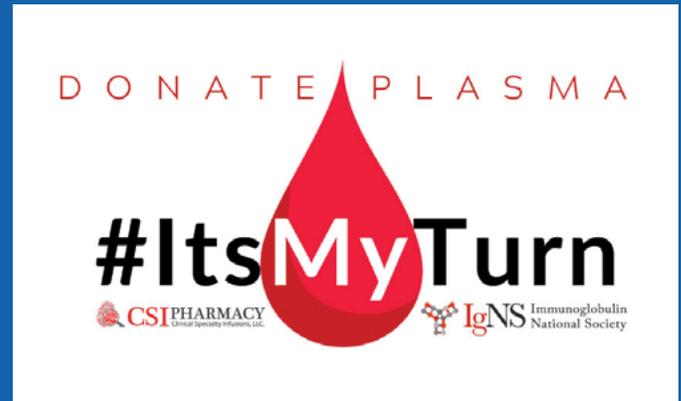
Plasma products would not be possible without plasma donors, who regularly commit their time and energy to give this gift of life. But plasma donations have fallen dramatically during this time of social distancing. When donations decrease, so do immune globulin supplies. If there is a shortage of Ig, patients who depend on this lifesaving treatment risk having to go a longer period of time between their infusions. They may even have to stop receiving infusions.

To ensure plasma availability for the future, patients can help by encouraging their communities to donate plasma. It is critical to keep a steady flow of plasma to make the plasma protein therapies that patients need to stay healthy.

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During this unprecedented time of fear and uncertainty, we witness the incredible daily sacrifices of healthcare professionals, EMS, military, police officers, and others working tirelessly to keep patients healthy and save lives. We have witnessed people coming together around the globe to support each other in any way possible. Donating plasma is one way that those of us who are not on the frontlines of the pandemic can make a difference.

Plasma donors are also compensated for their time, and an individual can earn as much as \$300-\$500/month by donating plasma.

IgNS has launched a social media campaign to help spread the word. If you or someone you love depends on Ig therapy, it will benefit you to mobilize those you know to become qualified plasma donors. Here's how:

1. Tell your friends, family, neighbors, coworkers, and others in your community to visit to locate their nearest plasma donation center by visiting [www.donatingplasma.org](http://www.donatingplasma.org)
2. When they donate plasma, take a picture before or after the donation process.
3. Post the image to social media using #ItsMyTurn and #IgNS.
4. Invite five social media friends to donate, too.
5. Have them tag the person they are donating for.

The #ItsMyTurn campaign has gained national attention and a lot of momentum. CSI Pharmacy, a corporate member of IgNS and a supporter of #ItsMyTurn, has developed a company-wide campaign in support of the campaign. The company has given team members time to donate during working hours, created a contest to encourage donations, and provided special recognition for those who recruit others to donate. To learn more about #ItsMyTurn, visit [www.ig-ns.org/itsmyturn](http://www.ig-ns.org/itsmyturn).



# Cultivating Resilience

Toby Speed

**R**ecently, I met up with six friends on a hilltop in Chapel Hill, where we watched the sunset, talked about our pets and kids and bad haircuts, and laughed ourselves silly. We also drank out of our own thermoses, wore masks when not sipping, and sat in camp chairs at least six feet apart. It felt totally normal—which seemed weird, and yet not. And I thought to myself, what a long way we’ve come since COVID-19 swept across the country and our town. What a long way *I’ve* come.

Adjusting to a new kind of normal is not new for me, but I did not see at first that the current crisis resonated with another time in my life when my world was turned upside down and I believed my courage was gone forever.

I think that’s because when devastation strikes, an army of fight-or-flight responses kicks in, and we’re not ready to see patterns. We come to the crisis, to the moment, and think only about our survival. When the pandemic arrived and made itself at home around the world, all I could think of was being hooked up to a ventilator in a hospital. That image is remarkably similar to one that lodged in my mind ten years ago, when

after months of painful symptoms, I was finally diagnosed with pemphigus.

On reflection, I can see other similarities between that time and this, particularly in the way I found my way back to a healthy and full life. Developing a chronic illness, especially a super rare one like pemphigus, is different in terms of its timeline and what we know about it than this invisible, rampaging virus. Still, I have found that the steps I personally took both times to retool my life have been very much the same. The feelings that struck me at the outset of my diagnosis— isolation, fear, anxiety, and a sense of uncertainty and unreality—were the same as the ones I felt in March when almost everything closed at once.

And feelings are really the key to bouncing back—or forward—to whatever is now normal. Brené Brown, my forever hero in navigating emotions and living wholeheartedly, says that resilient people are curious about their emotions and willing to lean into discomfort. She also reminds us that self-compassion and self-care are integral to the practice of wholehearted living, so that trauma is not heaped upon trauma. In my own resilience journey through the coronavirus and pemphigus

landscapes, I've found her words to be true. My path has included these elements: *upheaval*, *mindfulness*, *connection*, and *gratitude*.

## Upheaval

The beginning, the awful-feeling part, where the life we knew is suddenly gone, and the ground drops from beneath our feet. Being diagnosed with a rare disease I'd never heard of produced that kind of shock. Same when the coronavirus came to town. In the first two weeks after lockdown, I was so overwhelmed with uncertainty and anxiety that I couldn't concentrate on anything. Time expanded and contracted while I sat at the kitchen table, unable to write, to think, to imagine anything other than bleakness. I read the news incessantly, the way I read about pemphigus incessantly ten years ago. When I talked to my daughters or my friends, I spread my anxiety and gloom and compounded it for all of us.

How did I shift from gloomy inertia to the first step on my resilience journey? I looked for ways to be mindful, to connect with others, and to practice gratitude.

## Mindfulness

Mindfulness works far better for me than trying to force whole-cloth acceptance. I don't know how some people's brains can make the leap to accepting what seems incomprehensible and unfair—I know mine can't. But I can sit with it. I can breathe, stretch my body, light a candle. I can rest. I can cut some herbs growing on my deck and make something delicious, watch the hummingbirds at my feeder, and smell the roses. Journaling and hiking in the forest are other ways I focus on the now.

I like affirmations a lot, and I have them posted everywhere in my home. They're scribbled in my bullet journal and stuck to my computer on post-its. I keep a much-loved book by my bedside, *You Can Do All Things: Drawings, Affirmations and Mindfulness to Help with Anxiety and Depression*, by Kate Allan. It contains simple thoughts such as, "just try to stay calm and do what you can" and "progress is still progress, no matter how small."

Over time, my online searches have changed from cold medicine and pulse oximeters to water bottle fanny packs and bug spray. I'll take that as progress.

## Connection

The lockdown period, with all its inconveniences, has brought me closer to my family. I live alone, and every week for two months, my three daughters, two granddaughters, and I met on Zoom where we basically reveled in being together in our tiny squares. Two of my daughters live far from me, and since I'm not getting on an airplane anytime soon, Zoom has been a lifesaver. We continue to gather virtually when we feel the need.

Friends have been vitally important. I've had virtual happy hours and afternoon teas with my friends, and while screens can't replace hugs, they provide a real sense of connection and add value and energy to the day. And so does smiling!

We are hard-wired for connection, as Brené Brown says, and I agree. Enforced separation has been a big challenge with the coronavirus.

## Gratitude

It's easy to complain: not enough ways to have fun, too much uncertainty, too many risk factors to venture out, not enough structure to the day, too many messages, not enough knowledge, etc. I can find a myriad of things to complain about if I want to. But really, isn't this the way life is, filled with uncertainty and challenge? Uncertainty and challenge don't change the fact that I am still me and that I am enough, have enough, and do enough (another affirmation that hangs on my wall). I can greet life with all that's lacking or unfair, or I can greet it with enoughness. I make it a daily practice to notice something or someone I'm grateful for.

So, what have I learned about resilience? That crisis—diagnosis with a chronic illness or something swooping in from "out there"—is an opportunity for growth in disguise. That I become stronger and better able to cope in adversity. That normal is however I adjust my behaviors so that I have connection, fulfillment, and compassion for myself and others. That the unknown will become known and sustainable. And that I can cultivate hope through gratitude.

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*Toby Speed is a PV patient and author of seven children's books, lots of poetry, and a murder mystery. She has three daughters and two granddaughters and lives in North Carolina.*



# What Now?

## COPING WITH LOCKDOWN AND BEYOND

**Lynne Mitchell, MES, MEd, RSW**

**T**hrough this seemingly never-ending pandemic, we are all working to figure out how to live in lockdown. Among a variety of skills we never knew we had, we've learned to wash our hands while singing "Happy Birthday" twice, to work from home while schooling our children, and to socialize virtually. In a short period of time, our world has changed drastically, including how we work, obtain an income, socialize, go to school, see our doctors, buy groceries, care for our loved ones, exercise, and shop. The list of what we've learned to do differently seems endless, and we've also struggled with our usual, pre-pandemic challenges.

Depending on where we live, we are faced with different stages of "re-opening" and re-engaging with many aspects of life that have been put on hold these past several months. There is varying, and sometimes conflicting, advice on how to do this. We are being asked to cultivate another "personal normal" and are now faced with the additional challenge of how we will cope in yet another "new normal." We see businesses opening, traffic increasing, schools, daycares, workplaces opening, all at a pace we may or may not feel comfortable with. *How will we manage when faced with functioning beyond the safe and comfortable confines of our home?*

As we begin to think of re-emerging, it is normal to feel unsure about how to manage this next phase of coping with COVID-19. We must decide how we will re-emerge into the world, and how we want to do this as individuals with pemphigus and pemphigoid (P/P). We are not alone in feeling unsure. A recent Ipsos Mori survey published May 1, 2020, found that "more than 60% of Britons feel uncomfortable about the idea of going to bars, restaurants, gigs, sporting events, or using public transportation when lockdown is lifted. Less than half [49%] of those who are currently employed feel comfortable going back to work."<sup>1</sup> So, what is going on here?

When we were first confronted with the realities of the COVID-19 pandemic and had to go into lockdown, we likely felt some level of stress at having to manage all the complexities of modern life from the confines of our home. In Canada, for example, research by Nanos for the Mental Health Commission of Canada showed that in the month before the pandemic, 17% of those surveyed felt stress regularly. This figure has recently doubled.<sup>2</sup>

As a community of people with P/P, we've had to learn how to manage our lives during a pandemic while also managing a chronic illness. It only makes sense

that as we are being asked to leave our cocoon of safety and return to a more public, external life, that we feel stressed and worried. It feels strange to return to doing things outside the home that we have not done for several months. We may be unsure about the safety of public activities or the advice we are being given from public officials. This truly is uncharted territory. So, where does that leave those of us with P/P?

Marc Hekster, consultant psychologist at the Summit Clinic in North London, states that “anxieties about returning to life after lockdown form part of a wider psychological condition known as re-entry anxiety.” He explains that those who feel at greater risk of catching the virus (or experiencing complications from it) could feel more anxious. Those of us with P/P are certainly in that gray zone here, as we wonder whether we are at greater risk of catching the virus or experiencing greater complications if we do.

What causes us to feel anxiety, and what can we do to manage it? The brain under stress can be described from the perspective of two competing lobes: the limbic lobe, responsible for our more primal and emotional fear reactions; and the prefrontal cortex. The limbic lobe propels us into a fight-or-flight response of anger, stress, and anxiety. The prefrontal cortex is the rational, executive controller of the brain and has the capability to dampen the noise of the limbic system. The combined stressors of a pandemic and a chronic illness can cause the limbic system to operate in overdrive.

What can help dampen the noise of the limbic system as we consider some form of social or public re-engagement? First and foremost, it is crucial to seek advice from your doctor or health care provider. Having personal and relevant information from trusted sources will go a long way to help us develop a plan that makes us feel as comfortable and protected as possible. Everyone is in various own stages of living with P/P—diagnosis, treatment, or remission. This will have an impact on what activities are safe.

I recommend continuing to use the evidence-based strategies that worked for you during lockdown, and even in pre-pandemic times, such as:

- exercising and moving each day
- breathing, practicing mindfulness, and doing yoga
- sticking to a daily routine

- maintaining a balanced diet
- practicing good sleep habits and hygiene
- increasing serotonin levels naturally through activities you enjoy—this will help get the rational part of the brain back in gear (alcohol, caffeine, cannabis, and nicotine do not have the desired effect and should be limited)

I also recommend doing things that help us make sense of current uncertainties. These include:

- recognizing and naming our thoughts and feelings
- being kind to ourselves with no judgement on how we are feeling
- being patient
- reducing harmful behaviors (i.e., continuing to practice social distancing, frequent hand washing, and wearing a mask in situations where social distancing is challenging)
- maintaining social connections safely

Research shows that “being in the same boat” with others enhances our own experiences. I am a strong believer in the power of groups, real or virtual. Personally, I had planned for weeks to do an online yoga video, but never did. However, my friend sent me a link for an online class to attend together, and I haven’t missed a class yet!

It is important to reach out to your support system (including seeking professional help) when you feel overwhelmed by stress or uncertainty. These are unprecedented times both personally and globally. However, through the good days and the bad, and in our own way and our own time, we will figure out how to do this.

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1. Petter, Olivia, “Don’t push people outside their comfort zones too fast: How to deal with re-entry anxiety as lockdown lifts,” Independent, May 15, 2020, <https://www.independent.co.uk/life-style/re-entry-anxiety-coronavirus-lockdown-mental-health-awareness-week-a9516911.html>.

2. Nanos, Nik, in “As lockdowns drag on and stress levels increase, Canadians turn to soul-searching,” The Globe and Mail, June 13, 2020.

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*Lynne Mitchell is a Registered Social Worker in private practice in Toronto, Ontario, Canada. She was diagnosed with PV in 2015.*

# Visit the all new pemphigus.org



What are Pemphigus and Pemphigoid

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## We're here to support patients and caregivers

Our mission is to improve the quality of life for all those affected by pemphigus and pemphigoid through early diagnosis and support



Our new, redesigned website makes it easier to find what you need. From patients and caregivers to researchers and medical professionals, pemphigus.org is the most comprehensive place on the internet for pemphigus and pemphigoid information.

### Find a doctor

Looking for a doctor who knows how to treat pemphigus or pemphigoid? Find qualified medical and dental professionals in your area. Search our map and filter by specialty.

Find a doctor

### Ask a coach

The IPPF's Peer Health Coaches (PHC) are pemphigus and pemphigoid patients who help more than 1,200 patients and caregivers each year. These specially trained PHCs reduce patient anxiety and uncertainty while providing unbiased disease and treatment knowledge. You can find our PHCs engaging the community through social media, emails, phone calls, and in-person support. The goal of our PHC program is to ensure we help every person who needs assistance in the shortest amount of time possible.

Ask a coach





# Finding Joy in Laughter

Barbara Hee

**Do you love a good laugh?** Do you love to laugh until you cry? Until your sides hurt? So do I. But back in 2000, I wasn't laughing very much. My symptoms started with a small, sensitive area on the roof of my mouth. Eight and a half months later I had sores throughout my mouth, down into my throat, and up into my nasal passages. It hurt to swallow, and I could hardly eat anything. I had been to so many doctors when I finally called my primary physician, and he said that he either had to help me or put me in the hospital with a feeding tube. I finally saw an otolaryngologist who did a biopsy. I was diagnosed with pemphigus.

After quite some time and a lot of steroids, I started feeling like myself again. Around the same time, I saw an article about becoming a Certified Laughter Leader. My curiosity was piqued. I called for information about the program and spoke to a psychologist named Steve Wilson. There was a training offered near where I lived in Philadelphia, and I signed up. I learned so much during the training about laughter, laughing without a reason, and laughter yoga, which combines laughter exercises with yoga breathing techniques.

I learned about the benefits of laughter, such as reducing stress, increasing energy, enhancing the

immune system, making connections between people, and, of course, having fun. There were about 20 students in the training, and we practiced exercises like ho ho ha ha ha, laughing like a wicked witch or mad scientist, the vowel sound laugh, and many others.

I also learned about the importance of slowing down, practicing gratitude, and being flexible. One of Steve's sayings asks, "Do you want to be happier? Lower your standards." This saying was hard for me to accept as a former teacher, but I realized that sometimes good enough is good enough. I was often harder on myself than I would have been on anyone else, and I needed to adjust my way of thinking. Looking back, I believe that my stressful job as a sales manager contributed to the severity of my pemphigus.

Right now, I am safe at home because of the COVID-19 pandemic. Like everyone else, I have had to find ways to keep myself sane and nourish myself emotionally without any hugs and very little human interaction. Zoom has helped a lot—I have weekly meetings with family and friends. After catching up, we play a game. I have learned to share my screen to play Pictionary, and my family and I play games on apps like Kaboom and Jackbox.



Barbara Hee presented at the 2019 IPPF Patient Education Conference in Philadelphia, PA.

**Here are some additional suggestions for coping right now:**

- Turn off the news. Let your exposure be for what you need to know, not a steady diet.
- If you're religious, keep grounded and connected to your church. If your church doesn't offer services online, find another one that does.
- Call a friend or relative just to share a joke or talk about a funny video (sharing or forwarding the video is not the same).
- Exercise with a partner. Since I'm unable to attend my yoga class at the gym, my friend and I find a class on YouTube to do together, but apart. Afterward, we critique the video. There are plenty of choices, different experience levels, and many are free!
- Check out laughter yoga videos. A man named Jeffrey Briar holds daily laughter yoga classes on Facebook, and there are sessions saved on YouTube.
- Stay busy by doing a word search, organizing the drawers in your house, or baking bread. I often play Scrabble against myself. Some days I play two games, and I always win!

I spend a lot of time doing watercolor paintings, working in the garden, taking walks, reading, and watching TV (try watching a fun show and laughing out loud). If you haven't laughed by the end of the day, look in your mirror when you brush your teeth and make a funny face. Laugh! Your body and spirit will thank you.

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*Barbara Hee is a former teacher and sales manager. Barbara became a Certified Laughter Leader in 2003 and has presented programs to many groups, including teachers, nurses, recreational therapists, veterans, seniors, teens, and young children. She has three grown children, four grandchildren, and lives in Philadelphia.*

We surpassed our \$40,000 goal!

*Thank you*

The IPPF Community Hope Fund was launched at the beginning of May in response to the COVID-19 pandemic. Thank you for helping us keep hope alive.

Thank you to our corporate matching partners, Principia Biopharma and argenx, for their much-needed support during this campaign.



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