IN THIS ISSUE

FEATURES
4 Chasing Down Pemphigus & Pemphigoid
   Todd Kuh
5 Orphan Disease & Drugs
   Michelle Greer, RN, MBA
9 Fiftieth Anniversary Reflections
   David Zaret
10 Patient Story
   Brent Donaldson
16 Support Group News
   Boston: Ellen Levine
   Tri-State (NY/NJ/CT): Esther Nelson

DEPARTMENTS
3 From the Top
   William Zrnchik, MBA, MNM
6 Awareness Update: Patient Educators
   Patrick Dunn, MFA
7 Psychologically Speaking: New Year & New Beginnings
   Terry Wolinsky McDonald, PhD
8 Research Highlights: IL-4: Potential New Pemphigus Treatment
   Michelle Atallah, PhD

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As the holidays approach and 2015 draws to a close, there is much to reflect upon—and even more for which to be grateful. Join us in celebrating our many accomplishments, great and small, made throughout the P/P community this year such as:

- **NORD’s Abbey S. Meyers Leadership Award**
- **2015 Patient Conference** in New York, NY
- Increased advocacy efforts
- 1,000 dental students educated on P/P!
- PemPress, our new online news and information section
- Active Support Groups in CA, FL, NY, and TX

And yet with these distinctions, we do not rest on our own achievements, continually raising our own bar to fulfill our mission. As we strive to provide remarkable support and education experiences, we have also embarked on very challenging and significant initiatives to improve your quality of life:

- Post the Quarterly archive on our website
- Patient and physician education portal
- Downloadable resources
- Videos from P/P experts
- 2016 Patient Conference in Austin, TX

William Zrnchik, MBA, MNM
IPPF Chief Executive Officer
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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

These are just some highlights of a very dynamic time at the IPPF. I am so proud of the IPPF team putting in many long hours to improve patient quality of life. You see the results of this in everything we do—from answering your call or email, to planning events, lectures, and conferences. To help us continue growing programs and extending our reach, I encourage you to support the IPPF. Challenge your friends and family during our Holiday Fundraiser and $100K Challenge Grant. Each person who makes a donation will receive a pair of our #healourskin sunglasses and all “new money” is eligible for matching by a generous community member.

No matter what your P/P role is (patient, caregiver, physician, friend), we are all ultimately united through a common hope, an uncommon bond. Thank you for all you do in the P/P community!

From all of us here at the IPPF to our entire pem-family, we wish you a safe and happy holiday season!

Questions? Comments?
www.pemphigus.org

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Chasing Down Pemphigus & Pemphigoid

Todd Kuh

Prior to December 2010 I was a healthy, active person who had a passion for bicycle racing. After being diagnosed that December, I suddenly was a pemphigus patient and no longer an athlete. My physician informed me shortly after my diagnosis that I would not race again. He explained that physical and emotional stress must be carefully monitored and controlled from that moment on, as stress could trigger the disease. As I sat in the exam room I heard “chronic disease,” “no known cure,” “painful,” and “potentially life threatening,” and I wondered how I would tolerate this new reality.

On my way from the physician’s office that afternoon to the pharmacy to purchase my bag of medications (trying to figure out what had just happened to my life), I decided to take one last bike ride. As I rode that afternoon, still feeling strong from the countless hours of training, I suddenly realized that I would never feel this way again.

I always believed that I was blessed to be able to ride and race my bike and never took a single ride for granted. Throughout my medical treatment, I leaned on friends, family, and lessons learned from training and racing to provide me with the positive attitude I needed to overcome this disease. Although I practiced a healthy lifestyle prior to diagnosis, I implemented a revised health and medication program that would maximize the treatment I received.

After nearly three years of intensive treatment under the careful watch of Dr. Sergei Grando at the University of California, Irvine, School of Medicine, through healthy lifestyle choices and with the incredible support from friends and family, I’m in remission.

Dr. Grando again cautioned me of the factors that could contribute to relapse, which included physical stress. He assured me that should I choose to return to training and bicycle racing, my remission would most certainly be brief.

I realized that a healthy lifestyle incorporates exercise, which of course would be moderate in my case. With Dr. Grando’s approval, I began cycling again. As the months passed and my fitness slowly began to return, I realized that I was ca-
Orphan Disease & Drugs

Michelle Greer, RN, MBA

Chances are you have wondered why there are not more treatments available for pemphigus and pemphigoid or, at a minimum, why there is not more research underway for these conditions. There are a few reasons for this and, unfortunately, it’s something not easily solved.

First and foremost, pemphigus and pemphigoid (P/P) represent a rare group of conditions. A rare disease is also referred to as an orphan disease, defined as one that affects fewer than 200,000 Americans. Drug companies typically spend money on research and development for diseases that affect larger groups of people.

In 1983 the Orphan Drug Act was passed. This act incentivizes research for treatments of rare diseases. The three main incentives include federal funding grants to initiate clinical trials, tax credits of up to 50 percent, and an exclusive right to market drugs for a period of seven years from FDA approval date. Since 1983 the pace of both new medications approved for existing diseases and existing medications approved for new indications (like orphan diseases) increased.

Studies on rare conditions like pemphigus and pemphigoid are challenging because it is difficult both to attract participants and, subsequently, to receive FDA approval for treatments for these conditions. Not only are these diseases rare, but most patients typically have had difficulties being properly diagnosed and receiving effective treatment for their condition. When a placebo is involved, it means there is a chance of going without treatment, which may lead to relapse. Although rescue protocols for this are in place, it can still be scary to some people.

Other challenges to recruitment into orphan drug trials include poor disease awareness among physicians and a small number of physicians who actually treat the con-
By sharing their stories with students at dental schools in the United States, the IPPF Awareness Campaign’s Patient Educators seek to draw increased attention to pemphigus vulgaris (PV) and mucous membrane pemphigoid (MMP). Each session consists of a short clinical video on PV/MMP followed by a Patient Educator presentation and Q&A session, combining clinical information with the emotional appeal of a real patient’s struggle with delayed diagnosis.

Since March 2014 Becky Strong and Hannah Heinzig have presented to a combined 1,705 students, faculty, and staff at 12 schools. Steady requests for future presentations put the Awareness Campaign on track to surpass its goal of visiting at least 19 dental schools by the end of 2016.

To see Becky and Hannah in action, check out the new Patient Educator highlight video at pemphig.us/pe-highlights.

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.
This newsletter will likely arrive sometime during the winter holidays. Ah, holiday season—a time for so many traditions and emotions: joy, sadness, great expectations, disappointments, turkeys, traditions, family, gifts, trees, menorahs, Santas on every corner, movies and commercials that make you laugh and cry with great memories, and personal grieving and losses. And surely this is not an exhaustive list. Reflecting on your own list may help you to understand all of your own emotions triggered by the season. I liken my own roller coaster of emotions to being on extra prednisone for a few weeks, something many of you can relate to.

This season also marks the end of the previous calendar year and the beginning of the new one. It may have been a fabulous year in terms of your condition and the sometimes beneficial outcomes that happen at a more personal level; maybe you finally got properly diagnosed, started treatment or went into remission, met people face-to-face or online who “get it,” or made new lifelong friends. It may have been a year of flares and trying new treatments that didn’t work or aren’t getting insurance authorizations. All of this will replay for so many of you when the clock strikes midnight on December 31, that one minute of the year probably gets more attention than any other: endings and new beginnings. It seems like a lot to fit into 60 seconds, and it is.

Some people will make expensive dinner reservations or plan celebrations that they cannot afford, some will go to bed early or stay up in pajamas with a quart of ice cream and watch New Year’s Eve in New York City or locally. Others will get together informally with good friends or family. Many may use the holidays as an excuse to drink alcohol in large quantities, either in celebration or to drown their sorrows. Some people will go to bed early and sleep through midnight and the beginning of the new year; others will party hard. Whatever the case may be, everyone wakes up to a new year and a new day.

There isn’t just one way to celebrate, and everyone is not alike. People have lots of tradi-
IL-4: Potential New Pemphigus Therapy?

Michelle Atallah

The immune system is composed of many different types of immune cells. A subset of these cells, called T cells, play a significant role in a variety of immune responses including infection, tumor control, and inflammation. T cells secrete molecules called cytokines, some of which are pro-inflammatory, and others of which are anti-inflammatory. Under normal conditions there’s a delicate balance between pro- and anti-inflammatory cytokines. This allows the body to mount an effective immune response to fight off pathogens while maintaining enough regulation to protect the body against autoimmunity. When this balance is disrupted, autoimmune diseases such as pemphigus can develop. In pemphigus, excess IL-4 is thought to contribute to the symptoms of the disorder. This indicated that IL-4 may be in part responsible for the worsening of symptoms during active pemphigus episodes. As a result, the authors suggest inhibiting IL-4 as a way to prevent this process.

Like cytokines, T cells also come in several varieties which can be either pro- or anti-inflammatory. In addition to its possible role in regulating autoantibody classes, IL-4 has been shown to affect the fate of T cells during development towards a subset called Th2, which has been shown to play an active role in pemphigus: pemphigus flares often occur when the composition of T cells in the body shifts towards more Th2 cells. This provides another mechanism by which inhibition of IL-4 may help to better control pemphigus.

There are several examples of cytokine inhibitors on the market for other autoimmune diseases. Drugs that block TNF (tumor necrosis factor, another cytokine) have been approved to treat Crohn’s disease, rheumatoid arthritis, and ulcerative colitis, among others. Additionally, there is one anti-IL-4 treatment, Dupilumab, on the market. It is currently approved to treat asthma, and has shown some efficacy in other allergic diseases as well. While it has not yet been tested in pemphigus, it has the potential to be a novel therapy. The current results suggest that targeting cytokines may be a novel way to treat pemphigus.

In an article published in the journal Cytokine in October 2015 (doi:10.1016/j.cyto.2015.09.017), researchers in Tehran, Iran, discuss using a drug that inhibits IL-4 as a therapy for pemphigus. Previous research had shown that pemphigus patients have elevated levels of a specific type of antibody (called IgG4) during the active stage, while a different antibody class (IgG1) dominates during remission. IL-4 was then shown to play a role in inducing B cells, the immune cell type that makes antibodies, to produce more IgG4. In pemphigus flares, excess IL-4 is thought to contribute to the symptoms of the disorder. This indicated that IL-4 may be in part responsible for the worsening of symptoms during active pemphigus episodes. As a result, the authors suggest inhibiting IL-4 as a way to prevent this process.

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Michelle Atallah is a member of the IPPF Board of Directors and a graduate student in the Cancer Biology PhD program at Stanford University in Palo Alto, California.
In August 2016 I will observe two anniversaries: it will be fifty years since I was diagnosed with pemphigus vulgaris, and fifty years since I took my first dose of prednisone. I have been taking prednisone ever since.

Being diagnosed in 1966 (at age 18) makes me a survivor of the “middle ages” of pemphigus treatment. The dark ages, of course, were the years before there was any treatment at all. By 1966, corticosteroids were well-established, and PV was no longer fatal. However, while some immunosuppressive drugs such as Imuran® were available back then, they were not used widely for pemphigus.

I was treated initially at the Rochester Mayo Clinic and there, as at most medical centers, it was all prednisone all the time. You were given high-dose prednisone to get the disease under control, and then the dose was reduced very slowly, sometimes over a period of years. In my case, it took three years (with a couple of flare-ups along the way) to get to a point where I had no active PV and was on a low enough prednisone dose that I could resume most of my normal activities.

I then enjoyed three pretty good years, until I experienced my worst-ever flare. One reason the flare was so bad is that I delayed getting treatment. I was trying at the time to complete a graduate degree, had a nice group of friends, and, most important, had recently met my future wife. I didn’t want to leave to undergo a disabling course of steroids. So I convinced myself at first that the flare wasn’t really serious, and went on convincing myself until the lesions in my mouth and throat got so bad that I couldn’t eat solid food. At that point it was back to the Mayo Clinic!

I was treated initially with
Patient Story:
Brent Donaldson

I live in northern Minnesota, up near Duluth, and I am a 55-year-old person who is healthy in every way. So this disease really came out of nowhere.

I first started noticing issues this spring with my gums. They started to get irritated and were receding, blistering, and losing skin. I was going to my dentist, and after several visits and trying different dental treatments from March to May, he finally said he had no idea what was going on and referred me to a periodontist in Duluth. Dr. Alltiere examined me on June 26, and besides the current condition of my gums, I also told him I had noticed blisters that would just “pop up” in my mouth for no real reason. He then asked if I had any dermatological issues; at this time I had two small spots on my chest, but I did not think they were related. He said that what he suspected was going on was not a dental issue but a dermatological one. He suspected an autoimmune disease, and in our conversation I think he mentioned the terms pemphigus or pemphigoid. He said I needed biopsies and recommended that I go to the Mayo Clinic. So he referred me to Mayo, but I could not get there until the end of August.

The next week is when things started to spread. The spots on my chest that I now know are lesions grew. I also was noticing more lesions starting on my chest. We were going on vacation over the Fourth of July, so I went to my family doctor to see if there was anything that could be done for these lesions. She took a punch biopsy of one of them for analysis. We went on vacation and things kept getting worse. The lesions on my chest were getting larger, and then I noticed that my scalp was having issues. These lesions were spreading on my scalp, and washing my hair was a very painful ordeal. I was communicating to my doctor that I needed to get into Mayo sooner, and she contacted Mayo to get my appointment moved up.

I had noticed blisters that would just “pop up” in my mouth for no real reason.
While we were driving back from our vacation, we got the results from the biopsy. Good news, no cancer or tumor, but indications of pemphigus/pemphigoid as well as another related antibody were present in the sample. By this time I had lesions starting on my neck, back, and shoulders, but my scalp was the worst.

I got word from my doctor on July 17 that my case had been upgraded to “Stat” at Mayo, and the next day I got the call to be down in Rochester, Minnesota, on July 21. I had my first appointment with the dermatological department at Mayo, and they put me through the wringer with biopsies, blood work, and chest x-rays. Because I am a fairly “young” healthy person, they wanted to make sure there was nothing else going on that could have triggered this, like cancer or a tumor. They, too, suspected pemphigus, but I had some of the pemphigoid blisters as well, so they were not one hundred percent sure until the blood test results came back.

At this point they put me on 60mg of prednisone and scheduled my next appointment for August 7. After one week we increased the prednisone to 80mg. In the meantime the blood test came back, and my official diagnosis was pemphigus vulgaris. In this time frame I was still getting new lesions on my body, and my scalp was getting worse. It had been by far the most debilitating thing I had ever experienced. The lesions on my body and face I could deal with by covering them up with bandages. But any stimulation to my scalp, such as air conditioning, wind, or sun, was excruciating. I started by wearing a hat, then I had to completely cover up my head with biker do-rags in order to be out of the house. Fortunately, with my job, I can work from home, which I have been doing since July. Otherwise I would have been on medical leave, staring at walls in my house this whole time.

When I went for my August 7 appointment, my doctor added 2,000mg of CellCept® to the prednisone. She also said that if that didn’t work, then the next step would be IV infusion treatments with Rituxin®, with the goal to completely shut down my immune system. I asked her how probable she thought this would be, and she said it was looking like we would have to go down this road, as I was a very aggressive case. Can’t tell you how “thrilled” my family and I were to hear this! We scheduled my next appointment for September 4.

Adding the CellCept® to the prednisone worked; my lesions are got better and shrank, my scalp started healing, and I felt stronger. It looked like I would not need an IV Infusion. In fact, we cut back the prednisone to 60mg and increased the CellCept® to 3000mg.

At my October 4 appointment, since I was feeling good and my symptoms were improving, my dermatologist wanted to get me off the high dose of prednisone. So we started to reduce the dosage to 30mg, and then again in November to 25mg. She did not need to see me until the end of November. However, as October went along on this reduced dosage, I could tell that things were not progressing in the right direction anymore. My scalp worsened again, and the lesions on my cheeks did not change a bit. I also did not feel as good or have as much energy anymore. By the time November came I knew this was not working and now I would need IV infusion treatments with Rituxan®. I had been communicating to my doctor that we need to get the ball rolling on Rituxan® treatments. At my November 24 appointment my dermatologists took one look at me and said, “You are right, this has not been working!” So, my first infusion treatment was Friday, December 4, with a second one scheduled for December 18.

I’m praying this will finally lead to remission.

Brent Donaldson is a PV patient living in Moose Lake, Minnesota.
I was capable of doing more than Dr. Grando or I believed I could. However, I battled the constant fear that my exercise program would trigger a relapse, which created unnecessary stress.

I connected with the IPPF and spoke with Victoria, a pemphigus patient who told me about her running and physical activities. We shared our stories and were surprised and encouraged to learn that we both successfully live moderately active lifestyles while in remission. We agreed that exercise contributes to a variety of health benefits in addition to our sustained remission. My conversation with Victoria simply changed my life and gave me confidence that I could live an active lifestyle, which further contributed to my emotional well-being. I'm certainly much slower and I don't go very far, but I cherish every pedal stroke!

Once I realized that I was capable of a level of physical activity beyond what I previously expected, I began to experience the calming meditative qualities that exercise provides. Simply, moderate exercise reduces stress. While this is certainly not news to anyone, it's critical for pemphigus patients.

It was at this time that Victoria and I realized that establishing a healthy program integrating sound nutritional choices, active stress reduction, and moderate exercise for all pemphigus and pemphigoid patients, through the IPPF, would greatly benefit these patients. Also, this program could serve as a positive fundraiser to further benefit patients with added patient support through the IPPF. We called the program Chasing Down Pemphigus & Pemphigoid.

Chasing Down Pemphigus & Pemphigoid is intended to provide hope and a new perspective to the patient community; raise funds for critical research studies, awareness, and patient support programs; and promote an active, healthy lifestyle as a critical part of disease management.

The program is an ongoing campaign that challenges every patient to make better nutritional choices, go for a walk each day, take a yoga class, meditate, take on a new hobby, or do anything that improves his or her health, attitude, and emotional well being. Challenge other pemphigus and pemphigoid patients by pinning on a number and racing (yeah, I said racing) a 5K (or 10K!) run while raising some cash for a great cause – you and the IPPF. Chasing Down Pemphigus & Pemphigoid is about proving that we can do more than we thought possible.

The IPPF is a small nonprofit foundation that provides important patient programming and support. While Chasing Down Pemphigus & Pemphigoid is first and foremost a year-round program designed to motivate and support patients in their efforts to live healthy and active lifestyles, it is also a critical fundraising campaign that assists the IPPF in continuing to provide all of the support we all greatly appreciate.

The following are a few recent Chasing Down Pemphigus & Pemphigoid activities:

Legislative Conference, Washington DC, September 29, 2015

I had an opportunity to attend the American Academy of Dermatology Association (AADA) Legislative Conference in Washington, DC, with IPPF Peer Health Coach Marc Yale and pemphigus patient Mariah Lowinske. Each year the AADA Legislative Conference draws approximately 170 attendees/delegates, which include dermatologists, residents, patient advocates, and representatives from the Association of Dermatology Managers/Administrators and the Dermatology Nurses Association. This year the AADA and IPPF delegates met with 212 congressional offices from 35 States, including 98 meetings with legislators. Mariah, Marc, and I attended several of these congressional meetings as patient advocates where we asked members of
the Senate and the House of Representatives to support important health care-related legislation that would greatly benefit pemphigus and pemphigoid patients. The response from legislators was overwhelmingly positive. I believe the message, as delivered by patients, was extremely impactful. It was exciting to see the public process in action, and I was proud to stand with Mariah and Marc as representatives of the IPPF.

Cerritos on Wheels Community Cycling Event, Cerritos, CA, October 3, 2015

In 2015 I set out to complete four cycling events as part of the Chasing Down Pemphigus & Pemphigoid fundraising program. On October 3, I completed ride number three of four, which was the Cerritos on Wheels 50-mile ride. For the previous 20-month period I carefully, gradually, and consistently improved my strength and fitness through cycling. My exercise program consists of closely monitoring my efforts on the bike, plenty of rest between workouts, and sound nutritional choices. I was surprised and touched at the generosity and support I received from friends, family, and coworkers as I rode to raise critical funding for patient support and to send an important message to the patient community that we can do more.

On October 24 I was scheduled to complete my fourth event, The Patriot Ride, in La Quinta, California. As the ride date approached, I was feeling the effects from the previous efforts and felt tired. I reminded myself that Chasing Down Pemphigus & Pemphigoid is about healthy lifestyle choices and helping other pemphigus and pemphigoid patients through fun and challenging fund-raising events, not checking off boxes on a training program calendar. With that in mind, I decided to rest (it is on the calendar for 2016!). While it takes me a bit longer to cover the miles, I never forget how blessed I am to be able to ride and hopefully be an example of what is possible for pemphigus and pemphigoid patients.

LA Support Group Meeting, Santa Monica, CA, October 3, 2015

The recent Los Angeles Support Group Meeting, held at the Santa Monica Library, was constructive and informative. Biofusion, a specialized provider of IgG therapy, generously sponsored the event and presented material illustrating the benefits of IvIg. Dr. Roy Vongtama discussed the importance of stress management for pemphigus and pemphigoid patients and then led a guided meditation session for the group. I introduced the Chasing Down Pemphigus & Pemphigoid program and discussed how the group could get involved and inspire other patients to also take control of their disease. Peer Health Coaches Mei Ling Moore and Marc Yale, along with former IPPF Board Member Lee Heins, did a fantastic job organizing the event, which included a wonderful and healthy lunch. Biofusion sponsored Chasing Down Pemphigus & Pemphigoid t-shirts as well as the always handy “show your support” orange IPPF sunglasses.

All in all, a busy and very rewarding week of Chasing Down Pemphigus & Pemphigoid. Check your mailbox and your email box in the coming months for Chasing Down Pemphigus & Pemphigoid articles on nutrition, stress reduction, exercise, support and patient stories (including your story!). Can’t wait? Email me at todd@pemphigus.org or Victoria at victoria@pemphigus.org and get going!

Todd Kuh, a member of the IPPF Board of Directors, works in local city government as an administrator and is a PV patient who lives in Newport Beach, CA.
120mg prednisone together with methotrexate. The lesions became less raw and I was able to eat, but nothing actually healed. After six weeks they withdrew the methotrexate and started blasting away with 40mg of prednisone every 6 hours. After a month of this I still wasn’t getting better, and my body was beginning to break down under the onslaught of steroids. In addition to moon face, irritability, and sleep problems, I suffered increasingly severe muscle weakness as the weeks went by, until I couldn’t get up from a chair without help. And after ten weeks of high dose prednisone (six weeks of 120mg and four of 160mg), I had to start daily insulin injections. Finally I was given Imuran, and that did the trick. I improved steadily after the Imuran kicked in, and was able to go home at last after spending almost six months at the Mayo Clinic, including five months in the hospital.

Taking prednisone for 50 years hasn’t prevented me from living a “normal” life.

With the help of the Imuran I was able to taper my prednisone dose far more quickly than I had before. I was able to discontinue the insulin a few weeks after coming home (and have had no problems since with high blood sugar), and was back in bicycle-riding shape within a few months. I continued to do well until, after a little more than two years on Imuran and low-dose prednisone, I had to have surgery for thyroid cancer. While there was no suggestion that Imuran caused the cancer, once you do have cancer you’d like your immune system to be as robust as possible. So I stopped the Imuran and had to rely once again on prednisone alone. Fortunately I experienced nothing more than a few oral lesions. However, I have never stopped experiencing those occasional oral lesions; and this is why I have never been able to wean myself entirely off of prednisone. Over the decades I have reduced my dose very gradually – currently I’m taking 5mg every other day.

Taking prednisone for 50 years hasn’t prevented me from living a “normal” life. My wife of 40 years and I have raised two daughters; I continue to work full time as a computer scientist/professor; and I remain physically active with tennis, hiking, bicycling. I can’t imagine that any pemphigus patient reading my story will have to take prednisone for 50 years – treatments have improved significantly and will continue to do so. But if you have to take the stuff for a while, I can tell you that it is manageable!

Since 1966 we have progressed from the middle ages of pemphigus treatment to a renaissance, with the introduction of rituximab and other treatments. Perhaps a golden age, when pemphigus can be cured once and for all, is not too far off.

David Zaret is a computer scientist at the Johns Hopkins Applied Physics Lab, and a member of the part-time computer science faculty at Johns Hopkins University. He enjoys hiking in the mountains, and plays seniors tennis twice a week. He and his wife Shari live in Columbia, Maryland.
To many, the holidays can be the perfect time for change and experimentation in life.

While it is the case that the winter holidays can be a source of increased depression and reactivation of grief and loss anxieties, it is worth keeping in mind that these also mark the new year and new beginnings, even if you're not strict about New Year's resolutions (complicated and difficult New Year's goals don't work for everyone). To many, the holidays can be the perfect time for change and experimentation in life. New Year's is both an end and a beginning, as is every day. I wish all of you a happy and healthy holiday season and new year.

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.

Michelle Greer is the Senior Vice President in charge of sales for NuFACTOR Specialty Pharmacy.
Support Group News

Boston Support Group Meets

Ellen Levine

On a beautiful early fall day in mid-September, the Boston Support Group gathered for an afternoon of camaraderie, support, and information-sharing. Eleven patients and caregivers came together stretching from all over New England, including Maine, New Hampshire, and Massachusetts. It had been a few years since Boston Support Group members had convened, so there was a lot of catching up to do! The meeting provided the opportunity to renew old friendships as well as to create new connections with those living with these rare autoimmune blistering diseases. Members included those who had been recently diagnosed as well as a few who have been living with disease for 10 - 30 years.

The goals of the meeting were to provide a supportive and safe environment for those living with pemphigus and pemphigoid and their caregivers; make connections and build relationships with patients in the Greater Boston/New England area; introduce the IPPF and how members of the Boston Support Group can get involved; and determine the structure and timing of future Boston Support Group meetings.

While the goals of the meeting were met, the majority of time was spent with attendees going around the circle introducing themselves; sharing the name of their physician; their type of blistering disease; when they were diagnosed; their past and current treatment; and one thing they’ve learned from their experience with the disease. Members had much to share about their experience, and people chimed in and contributed as information related to their own stories. Attendees learned there are many different treatment protocols for autoimmune blistering diseases; they discovered there is an absence of a standard treatment protocol for P/P. Attendees also learned that while they share similar diseases, patients respond to similar treatments differently. There is hope for everyone, however, in the form of several different treatment options.

Volunteers were also solicited to help staff the IPPF booth on the exhibit floor at the Yankee Dental Congress (YDC) in January 2016. The YDC is New England’s largest meeting for dental professionals seeking dental continuing education, as well as dental products, services, and resources. With over 25,000 dental professionals in attendance from around the US, YDC is the fifth largest dental meeting in the country and provides an optimal opportunity for the IPPF to create awareness and provide dental professionals with firsthand information about pemphigus and pemphigoid.

The support group meeting was cohosted by Ellen Levine and Sam Iwamoto. Sam kindly hosted the meeting in the lovely and spacious func-
The Tri-State Support Group meets every two hours on a Sunday morning in early November, led by Esther Nelson and Matt Koenig. Seventeen people came to this group meeting at a public place in New York City, the Citicorp Building Atrium in Manhattan. Sitting around a big table were fourteen people who had either pemphigus or pemphigoid and three concerned family members accompanying them. The attendees received IPPF orange sunglasses and informational materials, provided by the IPPF.

One by one, people introduced themselves, telling their own story and history; everyone listened respectfully, learning from others' experiences. We talked about when and how we were diagnosed, which doctor we have, whether we like them (or not), and doctors we are seeking. We also shared the medicine we are taking or have taken, as well as experiences and advice on food to eat, vitamins to take, doctor recommendations, and the importance of exercise and dealing with mental and emotional health. Some people commented that doctors' medical recommendations varied, and some discussed which doctors preferred which drugs and regimens, such using IVIG, rituximab, or not.

The meeting was so compelling that we didn't realize that we stayed together until one and a half hours past the scheduled time. One new person came, and the group suggested a highly recommended doctor that some of us currently see, Dr. Annette Czernik in NYC. After the meeting, the woman felt more hopeful about her life and comfortable, knowing that good treatment is available and that she is not alone, that others understand and can support her in this journey. One young woman came with her mother, who is from India. To help the mother, we, the group and the IPPF, connected her with the Rare Disease Organization in India and IPPF doctors, Dr. Ahmed and Dr. Sinha, who go to India regularly and understand the nature of pemphigus. Now the mother has the connections and possibilities to receive help in her country. Early that Sunday morning, one woman traveled almost three hours by bus, one way, from outside the tri-state area (an hour outside Philadelphia) to come to our support group for the first time, knowing that others with pemphigus can understand. Was it worth it, we asked? Definitely yes, she said.

Overall, it was a very successful meeting! As for future plans, we will probably meet every three or four months, possibly at the same place at the same time, but we will explore other venues, too. Suggestions were made as to where and what will take place during these meetings.

Ellen Levine is a PV patient who hails from Boston with long-standing ties to New England. She works for a foundation that supports leading scientists at Harvard Medical School and at institutions in Italy, in the pursuit of scientific discovery in the field of medicine.

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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 share your experiences and get the support you need.

To find others in your area, contact Noelle Madsen at noelle@pemphigus.org.

Esther Nelson is a PV patient who lives in Forest Hills, NY.
We think Laten’s pumpkin is perfect too!

Laten and I found this bumpy lumpy pumpkin at the patch yesterday. We saw it at the same time and he said:
‘Mom you like dat?! It look like, something-- I not know... It’s wrong.’
I shrugged my shoulders, told him ‘I think it’s okay’ and asked if he wanted it-- at first he said no. Like a big time no. And told me he wanted a ‘perfect pumpkin’. I said ‘okay, well there’s lots of nice ones here’ and pat the pumpkin softly and turned to look elsewhere.

But... Then he kind of lingered there and said, very slowly: ‘Mom... That pumpkin not normal. It’s not perfect... It gots all deez lumps and bumps!’ I said ‘Yep’.

And he asked me AGAIN: ‘mom you like dat pumpkin? You do? I said ‘YES- I like it. It’s different but it’s nothing wrong with it. Its kinda neat. Maybe that makes it special’. And suddenly Laten smiled so big I could see it through his allergen mask....

And he said ‘MOM DATS A LATEN PUMPKIN! You love a Laten. DATS a PERFECT pumpkin... CAUSE IT GOTS SPOTS!!!!’ I just nodded my head... Hugged him hard. And ultimately paid $20 for the perfect pumpkin nobody else wanted.
And today- we dressed him up just right. ‘Bestest most awesome pumpkin EVER’... According to Laten.

I agree.
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2. You support the P/P community by purchasing items designed by others affected by P/P.
3. The IPPF receives 20 percent of the proceeds from each purchase.

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