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LA Support Group, September 28, 2013
Sponsored by BIOFUSION
www.pemphig.us/ippf-lasg13

Houston Support Group, October 19, 2013
Sponsored by NuFactor
www.pemphig.us/ippf-hsg13
Summer is drawing to an end, kids are back in school, and the IPPF is preparing for our end-of-year activities. I want to thank everyone who helps us carry our mission to the four corners of the globe. Volunteers are becoming more and more important in our daily operations, and every bit counts.

Helping us in the office will be not one, but two Cristo Rey High School student interns. For the fourth year in a row, we welcome back Kevin Cruz. Kevin has spent the past few years entering data into our patient database, uploading content to the website and Facebook page (*who can forget his Chuck Norris quotes?*), and other IT functions. This year he is working on patient and caregiver guides to provide essential information and tools.

And we welcome Freshman Isaac Silva who will help on the administrative side as he learns about our mission, programs, and services. Isaac will also help with the patient and caregiver guides to help him learn more about our community and how the diseases affect patients, caregivers, and families.

William Zrnchik, MBA, MNM
IPPF Chief Executive Officer
will@pemphigus.org

The Canadian Prime Minister of Finance announced he had pemphigus vulgaris. Marc Yale visited Washington D.C. and spoke with members of the House and Senate. And our Awareness Campaign began to develop.

To help the IPPF with the Awareness Campaign, please join me in welcoming our new

“...awareness has always been an issue, but that is changing.”
Dear IPPF Community,

As the summer winds down, I have been reflecting on the terrific progress the Foundation has made so far this year. The Foundation secured a $75,000 grant from the Sy Syms Foundation to support various disease education activities. The Sy Syms Foundation (www.sysymsfoundation.org) supports education, the sciences, arts, and civics projects.

This year’s IPPF patient conference was the most streamlined in our history, even achieving a modest profit. We created new volunteer positions and have been growing the ranks of these wonderful people who help propel the IPPF to great things. We have also elected new board members, who bring energy and fresh ideas.

We continue to build our infrastructure, from incorporating better IT tools to developing fundraising plans to enhancing our newsletter to interacting with drug development firms to incorporating more efficient internal processes. We will continue to build Foundation infrastructure, which will enable us to better deliver on our mission. The Foundation is on the move.

In my last Quarterly message, I discussed the importance of volunteerism and encouraged everyone to lend a helping hand. I urge you to look at the IPPF website to view the types of skills and expertise that we are looking for, the types of projects that we could use help with, and profiles of some of our volunteers. If you are not sure of what you can contribute, contact the Foundation and we will find something that works for you. We are looking for any of the following: expertise, time, enthusiasm. In a small community like ours, even a few volunteer hours or a small project makes a big difference.

Best,

Badri Rengarajan, MD
IPPF President

If you are interested in submitting a story for print consideration, please contact Quarterly Chief Editor Mirella Bucci at mirella@pemphigus.org prior to submitting your story. She will assist you in preparing your article for publishing in an issue that relates to your topic.
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My involvement with the IPPF stems from an interest in immunity, autoimmunity, and rare diseases. As an undergraduate at Yale, I researched Familial Mediterranean Fever, a rare auto-inflammatory disorder. I learned firsthand how different it was to perform impactful, translational research on a rare disease as opposed to more commonly known diseases with accessible information. I also discovered the importance of physician and patient networks in facilitating progress. Since working with the IPPF, I have been continually inspired by the dedication of the members of the organization and the collaboration among the IPPF, patients, and physicians.

I first volunteered at the 2012 Patient Conference in San Francisco. Helping with attendee check-in offered me the opportunity to meet many stakeholders in the community, and sitting in on the educational sessions gave me an insight into the pathology and basic science of pemphigus and pemphigoid.

My first special project was creating a list of external conferences the IPPF may consider presenting at, or attending in general, to raise awareness, increase the Foundation’s visibility, and promote research and collaborations with the IPPF. This list included numerous conferences and events where the IPPF could improve its collaborative base and create new partnerships, as well as gather information on emerging treatments, healthcare concerns, and more.

My current project is creating a grant database to help identify possible funding sources for IPPF programs and initiatives. This includes support for existing projects such as the patient conference, as well as the potential to expand existing services. There are federal, state, local, and private grants within various topical areas, program or submission requirements, and filing deadlines. Having this information in one location will help plan around grant cycles -- and hopefully fund current and future programs.

This continues to be a great learning experience for me, both academically and personally, learning how a successful patient-centric, rare disease organization is run. The IPPF is an ambitious, active organization with a very noble cause, and I’m honored to have the opportunity to contribute in any way that I can.
Dog Days & Determination

Rebecca Oling, MLS, MA
IPPF Board of Directors and PV Patient

For many of us in the United States, the start of September means welcoming a new school year for our kids and grandkids and saying goodbye to summer days. For others, the start of September is actually the start of a new year. Either way, September can mean a new challenge and a fresh start. This is a good time for engaging with the IPPF and creating a positive fall experience! Volunteerism is a great way to boost your mood, and to help you feel connected and grounded.

Research on volunteerism shows volunteers enjoy better overall health, a sense of achievement, greater life satisfaction, larger social networks, and higher self-esteem (Barlow, 2005). In fact, volunteering is so successful at helping the volunteers themselves that current studies are now specifically looking at volunteering as a means of coping and success in the context of chronic disease management. Some studies show a “pronounced improvement on confidence, self-awareness, self-esteem, depression and role functioning” and reveal that participants enjoy “dramatic change in their lives in terms of how they thought of themselves and in how they related to others.” So all of this begs the question:

How might YOUR disease path change if you were more connected to the mission of helping others and improving outcomes for the IPPF community as a whole?

“You probably don’t need a ton of convincing. For you, it may more be a matter of finding the time and the right opportunity to use your skill set. Trust us... you have skills you can share with the IPPF and put to good use. And there are few organizations out there which could use that energy more than we can! Volunteering for you might be as simple as giving literature to area dermatologists and dentists or trying to talk with them for a few minutes about the disease. It might be doing a “low stress” fundraiser. Or, maybe you are up for a bigger challenge in response to a need you see—like the need to start a local area support group or become a patient speaker to educate young doctors in training. No matter what your personal goals or strengths, you have something to give. So, as you ease into the new year or just prepare for Fall, remember that volunteering gives you the opportunity to:

S hare Strengths
E mpower Yourself
P romote Positivity
T each Tolerance
E ngage Others
M eet Challenges
B e the Change
E xpress Yourself
R each Out

~Helen Hunt Jackson

“By all these lovely tokens, September days are here, with summer’s best of weather and autumn’s best of cheer”

CONTINUED ON PAGE 15...
Transitions
Terry Wolinsky McDonald, PhD
Clinical Psychologist

Living in the northeast (actually mid-Atlantic), it is still very much summer - with humid heat and lush greenery and flowers surrounding me outside - as I write this. Nature is very much alive and in all its glory. In another month or so, I know that the leaves will be changing colors and dying while retaining their extraordinary seasonal beauty. It is really quite remarkable how beautiful nature is when dying.

It doesn't feel like a death, but more like a segue into a new and different way of being in the geographical areas where we experience the seasons and annual changes. Changes and transitions are always with us; some are just more noticeable and harder hitting. It is a cycle that continues - even with global warming and human intervention.

As always, the only constant IS change - and so transitions are part of our lives whether we fight them every step of the way or accept and welcome them, learning from our experiences. Changes of any kind can take us out of our comfort zones, but are necessary for our individual journeys.

People are complaining about the very hot and humid summer we are experiencing, but it brings back memories of the old “dog days of summer” which I fondly remember growing up with in the 50’s & early 60’s - without the comfort of air conditioning or even fans. I have no idea how we did it, but we did - and had fun even while sweltering. Running through a “sprinkler” attached to a hose on someone’s grass was like a piece of heaven in those days, but nights were more challenging!

This made the season change even more eagerly anticipated; it always felt like summer lingered a bit too long. Of course, with age, the days, weeks, months and seasons seem to go more and more quickly, keeping us on our toes. No two years (or days) are exactly the same, which keep us guessing just as these rare chronic illnesses do.

There are less challenging days and more challenging days with tears of both joy and sadness/loss along the way. The days merge into weeks and then months. Seasons change and other transitions - some smooth and expected.

A lot of people become conditioned to dealing with crises, and encountering and overcoming problems and difficulties usually leads to more resilience - a very positive quality to possess. Unfortunately, a growing number of people seem very at ease with crises, seeming to live from crisis to crisis while not dealing with everyday life. This is not a natural way to go through life and leads to very real daily difficulties and unhealthy stress levels.

The studies on stress continue to highlight the negative aspects of the mind-body connection. No, not every ache, pain or serious illness is caused by stress; but stress-relief strategies that work can make everyday life “easier” (or less difficult) and make crises smoother to navigate. This can be thought of as a navigation system of sorts in our life’s journeys. Unfortunately the navigation system must be learned through training, experiences and successes and failures. Often we do learn the most from our failures.

We all go through stages and often with some back-peddling from time to time. These are NOT negative times. Think about an EKG; a flat line is not a good thing. The small ups and downs are totally “normal”, and it is only when there are extreme changes that they are harmful. That is when people need extra help and more and more often seek it out - or go back to a therapist or psychologist (or family member, friend, colleague) for a “tune up”.

Sometimes the positive coping tools are misplaced, lost, forgotten, rusty or no longer enough. Frequently, one of the most common initial diagnoses for patients is “Adjustment Disorder”, which usually passes once new tools and strategies have been learned, especially with a mind-
Pemphigus and pemphigoid (P/P) diseases share a common underlying mechanism with other autoimmune diseases such as type I diabetes, rheumatoid arthritis, and multiple sclerosis – essentially the body’s immune system attacks its own tissues. These diseases also have in common standard strategies for treatment, which often involve suppressing the immune system in order to blunt this detrimental action.

A study by Dr. Hossein Mortazavi and colleagues published in the Journal of Autoimmune Diseases (dx.doi.org/10.1155/2013/834295) shows this often comes at a cost – a greater likelihood of getting infections.

The immune system consists of a complex network of specialized cells including B cells and T cells. Cells like macrophages are also at play. B cells are a type of white blood cell that is generated in the bone marrow. The main job of B cells is to generate antibodies – generally in response to invaders such as bacteria and viruses. The antibodies bind to specific proteins or sugars on the bacterium or virus and are then recognized by T cells (collectively call ‘antigens’), which rush to the scene to act as ‘killers’ of the infected cell. In autoimmune diseases, B cells act in a somewhat confused or overactive way, generating antibodies against cells of the body. In the case of type I diabetes, the antibodies recognize antigens on cells of the pancreas, leading to an inability of the organ to regulate insulin in response to food intake.

In the P/P diseases, the confused B cells generate antibodies against antigens made by keratinocytes – cells of the skin. It is now well-understood that because of the common mechanisms behind the various autoimmune disorders, people who have one of these are more likely to have another of them. For instance, people who have eczema as children are more likely to suffer from food allergies and asthma as they age.

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How to Feel Good About Yourself After Diagnosis

Toby Speed
Author and PV Patient

In the days after being told that you have one of the diseases in the Pemphigus/Pemphigoid family, when you're running around filling prescriptions for your new, huge, seven-day pill container, it's hard to feel hopeful.

Maybe you've been looking for answers for months - and getting the wrong ones. Maybe you're finding it a challenge to take care of ordinary everyday things, like brushing your teeth because of painful oral lesions. Or you don't know how to explain to friends that you're miserable and not feeling up to your usual activities.

That's how it was for me. By the time I was diagnosed with PV nearly three years ago, I'd consulted five different doctors over five months and had a medicine cabinet filled with failed ointments, pills and rinses.

Because my symptoms were so widespread, and because the doctors I saw were not familiar with Pemphigus, I'd been told I had everything from allergies to cold sores to possibly cancer.

It was weird hearing doctors, whom I instinctively trusted, tell me that this or that was going on with me, and turn out to be wrong, time after time. Each doctor focused on his or her special area of expertise, ignoring the symptoms that didn't fit.

I remember calling one doctor to complain the medicine she'd prescribed wasn't working, and she told me I was using it incorrectly.

Another doctor simply increased the dose of what he'd given me, and a third told me that if a certain cream didn't work in two weeks, I should come back and be biopsied for cancer.

Frustrating!

Scary!

Finally I saw a doctor who said the magic words, "I don't know what it is," and referred me to a great dermatologist, who biopsied me and put a name to my condition. Under his care I began the slow uphill journey back to health.

For me, the hardest part was not the discomfort of eating or washing my hair or the harsh side effects from medications, unpleasant as they were. It was the sad sense that I'd lost something precious and my life would never be the same.

As I learned how to cope with PV over time I found out that, like other major life events, this experience offered a unique opportunity to grow and learn more about myself.

Some encouraging words, for those new to this journey:

CONTINUED ON PAGE 15...
The Power of Giving Back

No matter what your skill set, everyone has something to offer

William Zrnchik, MBA, MNM
IPPF Chief Executive Officer

The IPPF is looking for volunteers to help us with many of our education and support projects and programs, including in several newly-created roles. The three main types of positions we are looking to fill are Executive Board (CEO's senior staff), Special Projects Contributors, and General Volunteers.

The Executive Board heads up a “department” or initiative under the CEO. This could include efforts like managing our patient support programs, planning and running our annual Patient Conference, running fundraising events, volunteer management, and research and development. Other areas include accounting, collaborations, and project management.

The commitment would be for one year or the duration of the initiative, whichever is shorter. And we are open to ideas for new “departments” and initiatives, and will even tailor a position to an individual’s talents and interests. This role is ideal for people that are operationally-oriented and want a significant role within the foundation.

Special Projects Contributors (SPC) have special expertise, resources, and access to give the IPPF a short-time commitment revolving around a specific area. This allows individuals to make a substantive contribution that fits their interests and lifestyle. Example projects include:

- competitive landscape analysis
- review of clinical guidelines
- website and/or graphic design
- exploration of a specific clinical care question
- legal analysis of a specific issue
- accounting and investments
- technical writing and reporting
- building a data management platform for our patient registry
- development strategy

CONTINUED ON PAGE 14...
The same is true for the P/P diseases - patients with one of these disorders is more likely to suffer from one or more additional autoimmune disease (for instance, Sjögren’s syndrome or type I diabetes) than the general population is.

Medications, like rituximab, that target B cells generally can be very successful in leaving these rogue cells incapable of attacking the body's keratinocytes. But since B cells are necessary to ward off invaders in other sites of the body, when they are removed with medication, the body becomes susceptible to the very invaders it is meant to fight - essentially trading autoimmunity for immunodeficiency. To compound the problem, the lesions formed by the disrupted keratinocytes are much more prone to infections than intact skin.

In their study, Mortazavi and colleagues studied the histories of 155 pemphigus vulgaris (PV) patients admitted to a single hospital in Tehran, Iran, over a period of about three years. These patients were grouped into three categories based on the severity of their disease - either mild, moderate, or severe - and were treated similarly. Fourteen of the patients were diabetic.

After admission, the patients with minor disease were all treated with the same doses of corticosteroids and immune-suppressants: prednisone, and if they were suitable for azathioprine treatment, they received that as well; patients with moderate or severe disease were treated with either azathioprine or mycophenolate mofetil and all received prednisone at the same doses.

Among these 155 patients tracked throughout their stay in the hospital, 94 had some kind of infection - 42 had pulmonary infections, skin infections (from Staphylococcus aureus bacteria), or urinary infections (mostly from Escherichia coli bacteria), where 33 of these already had the infections when they were admitted. Nine patients acquired infections while in the hospital, and 52 had oral candidiasis (yeast infection in the mouth) and localized oral herpes virus “breakouts”.

During their stay, 94 of these patients had some kind of infection - 42 had pulmonary infections, skin infections (from Staphylococcus aureus bacteria), or urinary infections (mostly from Escherichia coli bacteria), where 33 of these already had the infections when they were admitted. Nine patients acquired infections while in the hospital, and 52 had oral candidiasis (yeast infection in the mouth) and localized oral herpes virus “breakouts”.

Given that they knew the history of the patients, the authors were able to make some correlations. As a sidebar, this is called a retrospective study, where the researchers look for the underlying cause (usually only a correlation) of a problem that has already presented itself. A prospective study, which is generally more difficult to pursue because of the need to find patients who have not already been treated, is done to answer a specific question.

In this case, the question would be “does treatment with immune-suppressive drugs lead to increased infections?” It is a subtle distinction, yet an important one. Here, in the retrospective study, the authors correlated the incidence of infection with not only the severity of disease, but also the presence of diabetes - the patients with severe disease or with diabetes were much more likely to have or acquire infections. The conclusion was that immunosuppressive therapy in PV patients is a significant risk factor for infections. As well, the presence of at least one immune disorder (diabetes) made the patient more susceptible.

The authors didn’t report on any correlations with the presentation of PV - whether it was mucosal, cutaneous, or mucocutaneous - had they seen an increased incidence of skin infection with cutaneous presentation, they may have concluded that the lesions themselves (vs. the treatment) were responsible for the increase.

This study and several related studies (of infection after PV treatment) in the medical literature present a challenge to the treatment of PV and other autoimmune diseases - the possibility of finding a way to very precisely suppress the immune system (or the very specific set of B cells that are at play) to a level that doesn’t lead to susceptibility to infection.

Mirella Bucci, PhD, is Secretary of the IPPF Board of Directors and a scientific journal editor living in San Mateo, California. She is a regular contributor to the Quarterly newsletter in the Research Highlights column.
fulness based cognitive behavioral intervention. Prescribed psychotropic medication may or may not be prescribed, and some are short-term, while others may be more long-term in more complicated cases, or when the person has deeper underlying emotional or psychological problems (e.g., bipolar disorder, recurrent depression, a personality or panic or other anxiety disorder).

Sometimes previously repressed underlying issues emerge and take longer to resolve. Financial, insurance, work, primary support (or lack thereof), physical illness and other social and environmental concerns can work toward or against the eventual resolution of problems. Being aware of these and of the larger situation always helps.

For me, I have spent 10 years on boards devoted to pemphigus and related diseases and have watched and participated in many changes over this decade. It has been an amazing and exciting time. I went from being a healthy and high-energy person with one long-term autoimmune condition that was under control (for decades) to developing new and life-threatening conditions. My previous chronic condition, along with other acute health issues at various times, probably gave me an advantage regarding resilience.

I went through the same basic stages as anyone else, but also felt very strongly almost from day one that it was all for a reason - for a purpose. I soon learned that the psychological and emotional components of these orphan diseases were not being addressed. It is, of course, always critical to get the disease itself under control, but I would argue that being as mentally healthy as possible and with a strong support group is nearly equally important. I have not been among the fortunate who have been in remission for any considerable length of time. My one partial remission included symptomatology that was atypical. That diagnosis was made and addressed; monitoring myself daily is routine.

After a particularly nasty and stubborn flare this year, I felt the need to make some serious new life decisions. I did use the Cognitive model of decision making, examining all the facts and then carefully weighing options, while taking a few steps back for perspective. I have made some decisive strategic moves, including stepping down from the IPPF Board of Directors. However, I will always remain very involved in the IPPF, especially where patient support is involved. This will allow me to have more time to make necessary decisions regarding my own health, volunteer and professional work and family. It is just one more life transition along the road.

The coming years will bring new and different challenges and changes, but these transitions are necessary and very positive. Our IPPF Board of Directors has several new and very capable and passionate people who will continue to lead this Foundation forward in new and important ways. It is a very exciting time for the IPPF and the welfare of all patients, families and friends.

My participation with the IPPF remains an integral part of my life, but it is a time to re-prioritize, take the time to smell the roses in the moment, enjoy the beauty of the fall/autumn leaves and then make snowmen or just watch the winter wonderland, before spring and the start of the next season.

I look forward to this transition and to the new and interesting places and opportunities which will be part of the next phase of my own personal journey. Not only do I not fear transitions, but I look forward to them and what they will add to my personal human experience.

Also, your Annual Meeting Committee is working hard to make the 17th Annual Patient Conference in Chicago, April 25-27, 2014, a fulfilling experience for all who attend. We are looking at trying more changes, based in large part on feedback from patients and their families and friends who’ve attended the conferences.

Yes, we are listening and making necessary changes. Please consider what special talents or interests you may have or have access to as we ramp up our volunteer system and add ad hoc members to committees. Those experiences will not only add to your personal journeys, but also the future of the IPPF.

And who knows? Maybe it will be a special and transitional time for you!

Terry Wolinsky McDonald, PhD, is a former IPPF Board member, PV patient, and a licensed clinical psychologist living in Pittsburgh, Pennsylvania. She is a regular contributor to the Quarterly newsletter in her Psychologically Speaking column.
• helping set up and negotiate an external collaboration
• developing a market access/reimbursement advocacy strategy

The SPC role is great for people that have a special expertise they would like to use for a short-term project. Volunteers are encouraged to propose their own projects as well.

And equally important are the General Volunteers. General volunteers contribute across a wide range of initiatives and events. Example include newsletter and website contributions, print and graphic design, Patient Conference preparation and on-site help, event planning, peer support, and community fundraisers (e.g., 5K run, bake sales, wine and cheese tasting, golf outings, etc.). This role provides an opportunity for anyone to contribute with as much or as little time as they can.

We encourage those interested to tell us about their talents and interests, and we are happy to find a way for them to contribute.

These are great opportunities for anyone that feels strongly about our community, wants to give back to the Foundation with their time and expertise, and wants to help grow our organization to deliver greater impact.

All volunteers receive acknowledgment in our newsletters and website, and they can list the experience or project in CVs, resumes, and related documents.

If you or someone you know would like to get involved, please contact me at will@pemphigus.org or by calling the office at 855-4PEMPHIGUS (855.473.6744) extension 103.

Helping the IPPF through volunteering is a great way to help us help others. That's the Power of Giving Back!
1. You will feel better, a little at a time. Celebrate the small steps as your health improves each day, each week and each month.

2. Remember P/P is just a small part of who you are. While it may loom large right now, it will command less of your attention as time goes on.

3. Keep a health journal. I found it extremely helpful – especially in those foggy prednisone days when I got lost in the middle of sentences – to record everything health-related in a notebook.

   I wrote down the details of every doctor visit, the questions I wanted to remember to ask, the answers I got, symptoms and feelings, medication doses and so on. I’ve now had my notebook for three years, and it’s so handy for keeping track of lab work, bone density scans and other treatments that occur at regular intervals.

   Writing things down also keeps them from swirling endlessly around in your mind and is helpful when talking to your doctor.

4. De-stress any way you can. At the 2012 IPPF Patient Meeting in San Francisco, we learned about the chemicals released by stress that aggravate autoimmune disorders.

   My favorite way to get rid of excess stress is by doing yoga. I also enjoy walking, and when I don’t have time for either of those, a few long, deep breaths do wonders.

5. Count on your friends at the IPPF. There’s a wealth of help at the IPPF. You can get one-on-one support from a trained Peer Health Coach, ask questions on the discussion forum or join the active email group.

   Online resources, dial-in Town Hall meetings with IPPF’s doctor-researchers, and annual Patient Conferences are other options. I made the mistake of waiting too long before getting involved with this fantastic organization.

6. Give back. Share a tip that worked for you or just lend an ear to help someone else who’s newer to P/P than you. See #5 for places you can jump in.

If you are interested in getting started, visit pemphig.us/volunteerIPPF for some ideas. You can also contact Will Zrnchik by emailing him at will@pemphigus.org, calling (855) 4PEMPHIGUS (855.473-6744), or talking with your Peer Health Coach about volunteering!

Rebecca Oling, MLS, MA, is a member of the IPPF Board of Directors, librarian, and PV patient living in Rye Brook, New York. She contributes to the Quarterly newsletter on a variety of topics.

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