

Quarterly

The Journal of the International Pemphigus & Pemphigoid Foundation



Special Section:

**RARE DISEASE
DAY 2016** p. 10



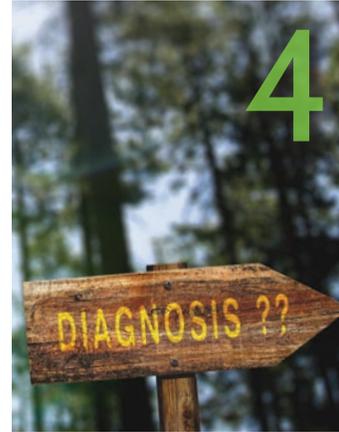
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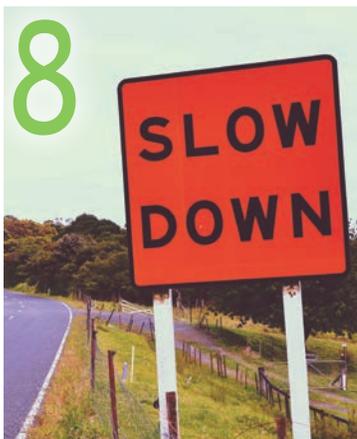
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Welcome to 2016!

We hope you enjoyed your Holiday Season! As soon as the calendar flipped from 2015 to 2016, we hit the ground running. The IPPF has a new **2020 Strategic Plan**. We raised over **\$115,000 during the \$100K Challenge** – and it was all matched! The **Awareness Campaign** continues to reach dental professionals in training and in practice at a constantly increasing rate. We have more **Support Groups** who are meeting more often. **The Quarterly** archives are now online. **Rare Disease Week** and **Rare Disease Day** were major successes. And this was just in the first two months!

We are in the planning stages for creating a printed materials library on P/P diseases, treatment, and lifestyle issues. **Educational portals** are planned for patient and dental education. Advocacy efforts will continue to increase as we are seeing the power of **The Patient Voice**. The **2016 Patient Conference** will be September



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The 2016 Patient Conference will be September 22-24 in Austin, TX!

22-24, 2016 in Austin, Texas (registration coming!). And we will be launching a new donor and fundraising platform very soon.

On to this issue. This issue is all about advocacy and awareness. They go hand in hand in educating the general public, elected officials, and medical professionals on not only what pemphigus and pemphigoid are, but also WHO WE ARE. The IPPF is working on an **Advocacy Toolkit with Global Genes**. When it's ready we will share it – and any advocacy or awareness resources we have – with you.

Dig into this issue and learn how patients from around the United States took part in advocating on behalf of all P/P patients and raising P/P awareness. When you're finished, I hope you are as inspired as we are in reaching out to elected officials and making The Patient Voice heard! Together, we can make 2016 a great year for P/P patients everywhere. ^{ippf}

Questions? Comments?

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

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My Pemphigus Challenge

Mei Ling Moore

My girlfriend Julie and I were at a restaurant one night during the first week in October 2001. We had fantastic sushi and enjoyed a couple of sakes. All of the chatter and laughter made for a fabulous chicks' night out. While we were waiting for the valet to bring us our cars, I felt an itch and a tiny bump on my upper back and I asked Julie to look at it. "Does it look like a bite?" I asked her. Julie answered, "Yes," so that's what we thought, and it turns out that's how my pemphigus journey began.

I went home and put some aloe with vitamin E on the bite and covered it with a small Band-Aid. The next day there were two more bites. In the ensuing weeks, I found about eight more bites, and pretty soon the Band-Aids weren't big enough to cover them. They grew to three inches by three inches in size. I bought Teflon™ pads and tape, because it turned out I was allergic to adhesive as well. They didn't look like bites anymore. They kept growing and hurting.

My upper back was completely covered – raw and oozing and extremely painful. It started to look as if I had open wounds from being hit by shrapnel. Clothing hurt, a strand of my hair touch-

ing them felt like a razor blade was cutting into me so I had to cut all of my hair off. I couldn't shower because the water hitting my skin hurt. I had to gingerly position myself down on my mattress, as contact with any surface was hurtful, and that took fifteen minutes. Sleeping was a challenge, as was keeping any type of clothing from sticking to me and ripping my skin off.

Three months of misdiagnosis and money spent on the wrong medications prompted anger, anxiety, and fear. A friend suggested bed bugs: I searched the Internet and then tore my bed apart. I was afraid to go to sleep for fear that I'd be bitten to death. I became extremely paranoid.

I was seeing one of the most respected dermatologists in Beverly Hills, [Dr. David Rish](#). He shared offices with [Dr. Arnold Klein](#) – Michael Jackson's doctor. You'd think these Beverly Hills doctors would know something. However, since Dr. Rish was out of town from October to the beginning of January, I'd only seen three of his associates who kept rediagnosing me without success. After three months of being stymied, Dr. Rish finally said, "I think I know what you have," so he ordered

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a blood test. The phlebotomist had to make a phone call to her supervisor because she didn't know what she was looking for. She had never been asked to find what Dr. Rish wanted. Imagine! Thirty years in her profession and she had not a clue!

Before I left the doctor's office, he told me not to look up **pemphigus vulgaris** (what he suspected I had) on the Internet, because I'd go crazy. Well, the power of suggestion is not lost on me, so I did look it up. What I read scared the hell out of me. Indeed, I shouldn't have looked it up. After that initial shock wore off, I went back online again.

An associate dean of dermatology at UCLA finally diagnosed me in February 2002. I began treatment with 100mg of **prednisone**. Needless to say, I was among the many patients being treated with steroids that got "moon face" and could have been mistaken for Humpty Dumpty.

The blisters had started on my back and ultimately traveled to my left ear. Then they moved to my scalp. Then onto my gums, which was truly scary as they turned white and were peeling back. Oral activity started inside my cheeks and then in the larynx. There were weeks when all I could consume was Ensure®. No proper eating for me.

I spent ten years on prednisone. My dermatologist felt I didn't need to take CellCept®, Imuran, or IVIG. My case is unique. In the final two years on prednisone, I tapered down from 5mg to 0mg. I have been in remission, without episode, since September 2012.

I spent ten years on prednisone.

During those ten years of treatment, I had great support from the **International Pemphigus & Pemphigoid Foundation**. Without the IPPF, I likely would have gone batty and been depressed. Since 2012 I have been a **Peer Health Coach** with the IPPF and am grateful to the organization and very happy to help other newly diagnosed patients. Since I know what it is like to be in their situation, I want to give the same support that I received. It is a blessing. 

Mei Ling Moore has been a Peer Health Coach for the IPPF since September 2012. In her old life, she was an executive assistant in production for the TV comedies, "Welcome Back, Kotter" and "Chico and the Man" and worked at major talent agencies in the entertainment business. She also worked at vet clinics, as she loves dogs. She lives in West Los Angeles.



Persistent Mouth Sores?

Working with Your Oral Health Care Provider to Reach a Diagnosis

Paul C. Edwards, MSc, DDS, FRCD(C)

Many individuals with **pemphigus** and **pemphigoid** (P/P) present with chronic mouth sores, often well before lesions appear on the skin or other parts of the body. These painful mouth sores tend to be persistent and present as red, ulcerated areas. In some cases—especially those with **mucous membrane pemphigoid**—lesions may predominantly involve the gum tissue. However, most people with P/P suffer lesions in multiple areas of the mouth, including the tongue, cheeks (buccal mucosa), wet surface of the lips, floor of the mouth, hard and soft palate, and throat.

Oral lesions are often subtle, especially in early stages of P/P. As a result, P/P are often misdiagnosed by both medical and dental practitioners as thrush, food or toothpaste “allergies,” poor oral hygiene, viral infections, or erosive lichen planus. Many patients with P/P are first treated on an empirical basis (treatment based on observation and experience without a definitive diagnosis), often with multiple medications, until one approach offers some relief. The relative rarity of these conditions mean they are often not on a medical or dental practitioner’s “radar” when assessing a patient’s oral lesions.

So if you suffer oral lesions, how can you partner with your dental health care provider to come up with a definitive diagnosis? A thorough review of your symptoms is critical. Make sure your dentist or dental hygienist listens carefully and asks detailed questions about your concerns, such as:

- How long have you had lesions?
- What areas are involved?
- Do you have any skin, eye, vaginal, or rectal involvement?
- What do the lesions look and feel like?
- Do the lesions move?
- Does your pain level and disease activity vary over time?
- Do you currently have any active lesions?

While early disease symptoms can be subtle, most of the conditions for which P/P are misdiagnosed are not typically chronic (with the possible exception of erosive oral lichen planus or chronic ulcerative stomatitis). Moreover, at least to a clinician with experience diagnosing and managing these conditions, the clinical appearance is quite distinct -- toothpaste allergies and poor oral hygiene do not lead to widespread, chronic oral ulcers!

The saying “diagnosis dictates treatment” is particularly relevant when it comes to treating

oral ulcerative conditions. Therefore, the best advice I can offer is threefold:

1) Your dentist or physician needs to take your complaint seriously and needs to thoroughly investigate your symptoms.

2) A diagnostic tissue biopsy is essential before your dentist or physician treats you empirically with antifungal, anti-viral, or corticosteroid medication.

3) If the clinician assessing you does not insist on performing a diagnostic biopsy, insist on being referred to a clinician with extensive experience in the diagnosis and management of oral lesions (e.g an oral and maxillofacial pathologist, periodontist, or dermatologist). ^{ippf}

Dr. Edwards is Professor of Oral and Maxillofacial Pathology at Indiana University School of Dentistry (IUSD). Prior to joining the faculty of IUSD he served on the faculties of the schools of dentistry of Creighton University and the University of Michigan. He is a Fellow of the American Academy of Oral and Maxillofacial Pathology, a Diplomate of the American Board of Oral and Maxillofacial Pathology, and currently serves as Section Editor for Oral and Maxillofacial Pathology of the journal *Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology*.

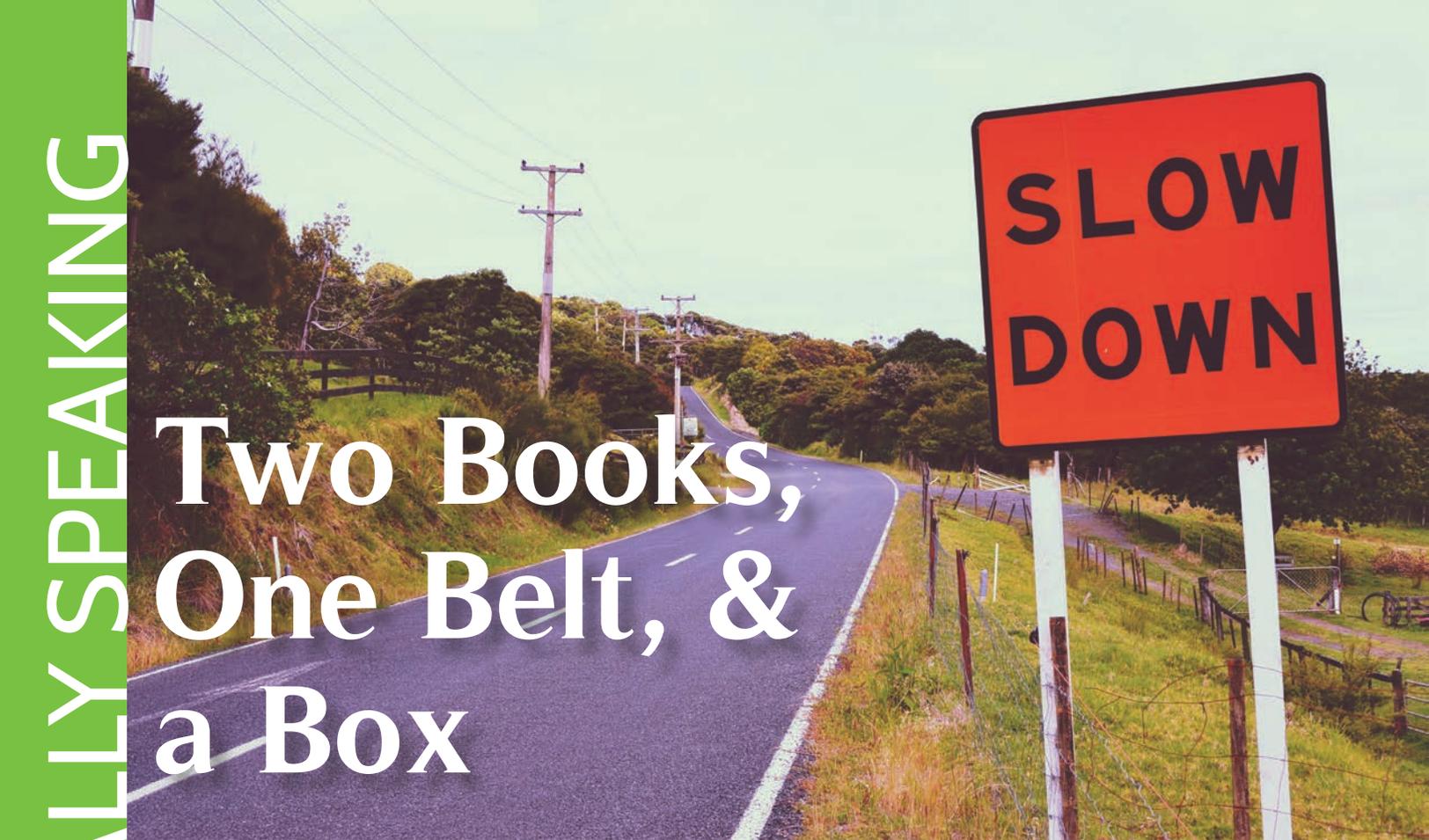


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The above article first appeared on PemPress, the IPPF's news site. Other recent articles include:

- “It’s Natural” Noelle Madsen addresses holistic treatments.
- “The Rarest Day of Them All” Will Zrnchik recaps Rare Disease Day with a great online companion to this issue’s special section.
- “Repurposing Drugs Matters with Rare Disease” Special contributor Candace Lerman discusses off-label drugs and the OPEN ACT.
- “Raising Awareness at Dental Conferences” Kate Frantz provides an Awareness Campaign update about reaching dentists via exhibitor booths at major conferences.



Two Books, One Belt, & a Box

Terry Wolinsky McDonald, PhD

I recently had to retrieve each of the items listed in the title of this article from my car after an “accidental” lapse in memory, and the incident got me thinking about my conditions (I have both [pemphigus](#) and [Sjogren’s Syndrome](#)). Many patients with pemphigus or pemphigoid are also struggling with other ailments—often other autoimmune diseases. There is no doubt that these conditions, and the medications we take for them, affect how we think, learn, process, and retrieve information, especially as we get older. Taking time to reach our goals and being mindful during the process can make accomplishing daily tasks easier.

With spring around the corner, this may be a good time to reevaluate your own journey. It can change any time you decide, and the changes do not need to be big ones. In fact, I recommend that you break down any big goals into small and doable ones, with the added benefit of giving you small successes as you continue to move forward. Now is the season to “spring forward.”

Cognition can and does change due to fatigue, mood, nutrition, lifestyle, illnesses, medications, and age. With Sjogren’s, there is a lot of talk about “foggy brain,” which sounds a lot better to me than “senior moments,” which might also be consistent with my situation. At a recent Sjogren’s support group meeting, the patients were asking an expert neuropsychologist speaker about their very real cognitive issues. Out of total frustration at the lack of being understood, one woman yelled out, “But have you ever found your pot roast dinner in the linen closet?” This sounds funny, but it doesn’t feel that way when it happens, which can be quite often. My husband still refers to the day we found my cell phone ringing in the refrigerator as a “cold call.” I remain not amused and somewhat disturbed that I can have such lapses, although I recognize that a sense of humor can and does help with keeping a more positive self image.

I know that my hearing is fine, as I’ve had it checked out, but I also know that I often miss the content of conversations if I am immersed in

something else. For me, I know that if I make eye contact with someone, I will hear, process, and remember what they are saying. I have trained those closest to me to make sure there is good eye contact if they have something important to share with me.

What I have difficulty with is something many people take for granted – multitasking. Once upon a time, I was an efficient multitasker, but once I became ill, I could no longer do it. It is at points

line drawn through it. In my mindfulness practice, I have a designated **NO STRESS** area where I can just allow myself to “be,” rather than trying to be in performance mode. I keep the lights low, perhaps with a lit candle, and furnish it with a comfortable chair and sofa. I have a particular painting which calms me down instantaneously. It is almost magical to “be” in the moment. Such practice is refreshing and can be done for as little as five minutes a few times a day.

The quality of our time as well as the final products of our actions increase significantly when we focus on one thing at a time and do this at our own pace . . .

like this when we need to retrain ourselves. How many times have you been watching a mundane TV program (I think of the Weather Channel) for hours and could not tell anyone anything about it? It has happened to me countless times. I think that a key to being able to successfully multitask is awareness. Beyond that, there is the matter of prioritizing and doing one thing at a time – and, if possible, doing it mindfully versus mindlessly. In previous articles, I’ve talked about the importance of mindfulness. In many situations, it is a valuable antidote to the buzz of thoughts, emotions, and behaviors we experience. I encourage you to practice mindfulness—becoming more aware of your actions and thoughts.

The quality of our time as well as the final products of our actions increase significantly when we focus on one thing at a time and do this at our own pace; you don’t need to rush just because so many others are always in a hurry, such that life can seem to be rushing by. In reality, this rushing around can be deleterious to our health. Think of a fast forward sign in a circle with a diagonal

While I was able to fairly easily retrieve those items I neglected in my car, the entire incident was annoying and totally unnecessary. I learned an important lesson; I was trying to do too many things and too quickly. I continue to learn and evolve with the knowledge that my illnesses are not in the driver’s seat; I am, and I fully intend to remain cognizant of that. Slowing down has added more quality of life to my journey, and I have not heard many complaints about what I do/ do not do. I feel more rested, happier, more in control, and more relaxed. If I ever need a reminder, I just think about those three B’s – the books, the belts and the box. [ippf](#)

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



RARE DISEASE DAY.ORG

In 2009, US Rare Disease organizations joined the already established European movement of Rare Disease Day, celebrated on the last day of February every year. Since

then, a major goal in the US has been to grow the number of State House events across the country. Rare Disease Day 2016 was the most impactful year with 38 states participating. These events are opportunities to meet face-to-face with elected officials and advocate for legislation that directly affects the rare disease community.

California rare disease supporters did not disappoint this year! On February 29, 2016 rare disease advocates, patients, caregivers, and legislators gathered at the California State Capitol to celebrate the passing of Senate Concurrent Resolution No. 108. This measure proclaimed the last day in February as Rare Disease Day in California for 2016 and all subsequent years to follow.

Assemblyman Katcho Achadjian (CA District 25 & Principal Co-Author of SCR 108) an-



nounced the resolution on the assembly floor. Rare Disease Day guests then proceeded to the Eureka Room of the Capitol building where representatives from multiple rare disease organizations spoke, including **Kristen Angell** from the National Organization for Rare Disorders (NORD) and the IPPF's own Executive Director, **Will Zrnchik**.

The passage of SCR 108 was a huge step forward for the rare disease community in California. Every year, we hope to continue to raise more awareness and advocate for more issues that affect our rare disease communities.

To cap off an already successful day in Sacramento, NORD and the IPPF educated more than 15,000 people on rare diseases and P/P at the **Sacramento Kings/OKlahoma City Thunder** NBA game at Sleep Train Arena. Just before tip-off, Will Zrnchik was interviewed about

Rare Disease Day and P/P. This interview was broadcast live to the entire stadium via the jumbotron hanging high above the court.

Immediately following the interview, a special Rare Disease Day and P/P informational video created by the IPPF's **Patrick Dunn** was played. The same video was played again at half-time.

Though the Kings' lost, the game was exciting. Enthusiasm was especially high in Section 123, which was filled with rare disease patients, family, and friends celebrating the communal effort to raise awareness for all rare diseases.

Throughout the game, NORD and IPPF staff passed out information and the always-popular **#healourskin** sunglasses, which provided another opportunity to educate fans about P/P.

Doris Chenier

We may have a rare disease but no one will know about it unless we use our voice to speak to people that can make a change.



Debra Levinson

There's plenty we can do this election year: Consider writing letters and making phone calls to bolster these pieces of legislation; email your member of Congress, which is made easy utilizing the automatic draft letters on rareadvocates.org; or take advantage of in-district lobby day opportunities to build relationships with your members of Congress. I am hopeful now with so much support we can help ourselves heal. We are the voices of the rare disease community with a common role.



Mary Lee Jackson

When I received an email about going to Capitol Hill, I got excited and thought it will be easy. But I was wrong it was hard work. I hadn't walked so much in all of my life. I felt good about what was done on Capitol Hill. It was worth all I went through to get the word out about rare diseases.



Paula Halicki

Not only was I representing myself, the IPPF, and the pemphigus/pemphigoid community, but I was also representing a lot of other people with healthcare issues who could not represent themselves. And quite a few who never will. Plus I told my story, and a Congressman listened.



Angélica N. García Romero

I had great meetings with the staff of the representatives and felt very accomplished. But to top it all, when I was taking my flight back to Puerto Rico, my representative was on the plane too! When all the turbulence stopped, I went up to him, and had the meeting right there.





The purpose of advocating in [Washington, DC](#) is to spread awareness and lobby for favorable legislation that affects the entire IPPF community. At [Rare Disease Week on Capitol Hill 2016](#), we had 7 members of the IPPF community advocating for:

- [HR 971/S1421 \(OPENACT\)](#): legislation that will repurpose “off label” drugs for rare disease indications that are not currently covered by the FDA
- [HR 605/S275 \(Medicare Home Infusion Act\)](#): legislation that will make it easier for Medicare patients to get infusions done in their homes
- [HR 1600 \(Patients Access to Treatment Act\)](#): legislation that would cap the amount that insurance carriers can charge patients for more expensive medications
- [S 2030 \(Advancing Targeted Therapies Act\)](#): legislation that would allow information learned in clinical trials to be used in the development of new therapies
- All Congressional Members to join the [Rare Disease Caucus](#)

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Support Group News

First Austin Support Group Meeting

Rudy Soto

Austin, Texas held its very first support group meeting on Saturday, January 30th and it went very well. There were three patients, including myself, and a few supporters. We were able to get to know each other on a personal level because it was a small group. We had discussions about our disease activity and medications, and the supporters that were present were also able to express what they go through and experience. We connected with each other and it was a great feeling. I am looking forward to the next meeting and hoping that we have more people attend and encourage them to bring their loved ones.



Rudy Soto is the Austin Support Group Leader and a PF patient.

Upcoming Meetings

Boston Support Group Meeting
April 2, 2016
1:00pm to 3:00pm (EST)

Houston Support Group Meeting
April 9, 2016
12:00pm to 3:00pm (CST)

Austin Support Group Meeting
April 23, 2016
5:00pm to 8:00pm (CST)

More information:
pemphigus.org/newsmedia/ippf-events



The South Florida Support Group with Dr. Weatherall (middle).

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: noelle@pemphigus.org.

Donate today! Help a patient tomorrow!

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