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   www.pemphig.us/ippf-hsg-jan14-2014

Houston Support Group, April 12, 2014
   www.pemphig.us/ippf-hsg-apr12-2014

   Chicago, Illinois    www.pemphigus.org/2014conference
Season’s Greetings! It’s that time of the year again and here at the office we are getting ready for 2014. But we still have another month to go, and that means finishing up 2013 with a bang!

Kate Frantz is settling in and getting the Awareness Campaign up and running; Monique Rivera has been busy processing donations and keeping the information flowing; Kevin Cruz has been working on patient and caregiver handbooks; Isaac Silva has been doing some web site work while learning more about the IPPF; Marc Yale and the Peer Health Coaches have been helping patients at an astonishing rate; and the Board of Directors and our Medical Advisory Board continue to be instrumental in shaping our future.

2013 Holiday Fundraiser. This fundraising season is shorter than usual with Thanksgiving falling where it did, but so far this has been one of our best efforts in recent years. Along with first-time supporters like Rana, Hartmut, Chris, Patricia, and Bob it has been great to see the names of long-time supporters like William Zrnchik, MBA, MNM
IPPF Chief Executive Officer
will@pemphigus.org

What do you get someone turning 20? How about a party in Chicago! The IPPF celebrates its 20th Anniversary in 2014 and we are planning an evening of food, friends, and fun at the 2014 Patient Conference. On Saturday evening (April 26, 2014) join us for dinner, our Annual Awards, and an Anniversary tribute followed by a Casino Night fundraising event. More information will be available soon! Proceeds go directly to our Patient Support programs. If you’re in Chicago, I hope to see you there!

2014 is now a couple minutes closer than it was before you read this letter. With Autoimmune Disease Awareness Month, Rare Disease Day, Pemphigus & Pemphigoid Education and Awareness Month (New Jersey...come on NJ SJR77!), 17th Annual Patient Conference, and more on the horizon - we need your help! If you’re interested in spreading the word and mission of the IPPF, call or email me and let’s do this together!

Thank you, Happy Holidays, and from my family to yours - Happy New Year!

Lillie, Joan, Alice, Yvette, Carol, Ellen, Jay, Sonia, Ed, Therese, and dozens of others who continue to support our important work. If you have not donated there is still time. And make sure to date your check accordingly so you get your 2013 tax-deduction!

Awareness and Education. If you missed the August buzz on Facebook, Rebecca Oling and MAB member Dr. Animesh Sinha were guests on Good Morning New Haven (Connecticut) talking about pemphigus, pemphigoid, and the IPPF. She followed that up with a trip to Houston, Texas, to participate in a 4-hour long video shoot for IPPF that will be added to the Giving Library (www.givinglibrary.com). Add to that scouting the globe for patient educators, helping people on Facebook, traveling to sit with patients and their families, working full time, and being “Mom, wife, daughter, and sister” and you can see why Rebecca is my hero!

Helping patients since 1994. It’s what we do.
Acknowledgements

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**Have a Question or Comment?**

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*!

*Quarterly* related: editor@pemphigus.org

Foundation related: info@pemphigus.org

Letters to the Editor: editor@pemphigus.org

Disease, Treatment, Lifestyle: phc@pemphigus.org

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**Got an Idea?**

If you would like to see a specific topic covered, or are interested in submitting a story for print consideration, please contact Quarterly Chief Editor Mirella Bucci at editor@pemphigus.org prior to submitting your story.

Examples include: product reviews, your disease journey/story, inspirational and motivational pieces, and things of interest to patients and caregivers.

We can assist you in narrowing a topic, copy editing, and preparing your article for publishing in an issue that relates to your topic.
On September 10th, I found myself in our nation’s capital ready to advocate for the IPPF and all its patients with my legislative representatives. It was the 2013 American Academy of Dermatology Legislative Conference and the first day back from a Congressional break. The United States was faced with the possibility of a military strike in Syria over their alleged use of chemical weapons; a looming budget crisis; and a host of other political issues. Would my members of Congress want to hear about a set of autoimmune blistering skin diseases that they have never heard of?

I have to admit that at first I was a little intimidated going to Washington D.C. and worried whether or not an ordinary citizen like myself would be able to make an impact on our government. I was surprised to discover that not only was I welcomed by my congressional members and their staff but that they truly wanted to hear my concerns.

I had this image that our system was so big that I was not significant, but found out that the opposite is true. I learned that the only real way to effect change was to act, participate and communicate. Most importantly, I realized if we all stand up and make our voices heard collectively we have the power to change policy.

The IPPF works hard every year to maintain relationships with Congressional Representatives and others who may wonder whether or not an issue concerns them.
Season’s Greetings
and
Happy New Year

IPPF Board of Directors, Medical Advisory Board,
Staff and Volunteers
The Journey Continues

Terry Wolinsky McDonald, PhD
Clinical Psychologist

Just as life is a journey, so is living with chronic illnesses like pemphigus or pemphigoid. In the last newsletter, I emphasized transitions along my personal journey. Chronic illness is an adventure no one signs up for, but once the diseases are triggered, life is never again exactly the same.

For those newly diagnosed, or their family, friends or caregivers, it can all seem unreal at first. There is a vague beginning to the new normal, as it takes time to get educated and to process the diagnosis and information. Even after there is an acceptance of the situation, it is overwhelming.

Everyday life becomes uncharted territory. One thing is for sure: now challenges seem to pop up a lot more. How the challenges are met will make the difference between function and dysfunction.

The pemphigus and pemphigoid (P/P) community is not a static one. Everyone goes through different stages in different ways, but with more similarities than differences. This is why the community continues to grow. People who have had very similar situations - and have made it through to the other side - are there to help you. Eventually, once your own life and illness have stabilized, you will have the opportunity to be there for others.

Some people will get more ill than others, and some people will respond more quickly to treatment. For everyone this is an adjustment – and again the degree of difficulty differs between people. Having an IPPF community, with a discussion group, a social media presence, award-winning newsletter and website, peer health coaches and volunteers (and more!), has helped many people along this journey in so many positive ways. Maybe YOU have been helped by one or more of our resources?

The IPPF works hard to ensure that no one has to go through this alone; this is not just helpful, but a bond, and one that strengthens everyone involved. It is a lifelong bond - one that keeps gaining strength. No one has to navigate this road alone any more.

This is the time of the year to give; but in our community, there is a need 365 days a year - not just one “giving” season. If you are not current-
No Disease is too Rare for Treatment

Mirella Bucci, PhD
IPPF Secretary

Rare diseases, including several autoimmune disorders, are getting more attention from drug-makers, according to a new report by the Pharmaceutical Research and Manufacturers of America (PhRMA), a consortium of 36 US-based pharmaceutical and biotechnology companies. In 2012 alone, 13 drugs for orphan diseases (“orphan drugs”) were approved by the Food and Drug Administration (FDA). Approximately 452 medicines and vaccines are in development for the nearly 7,000 orphan diseases worldwide.

Orphan diseases are defined as diseases with fewer than 200,000 patients. In total, however, across the nearly 7,000 orphan diseases, 30 million people in the US, or about 10% of the population, are affected by an orphan disease. The pemphigus and pemphigoid (P/P) diseases are considered “ultra-orphan” diseases because they are extremely rare. It is estimated there are only about 50,000 new P/P cases each year worldwide, with only a few thousand of those being in the US.

Rare diseases tend to be more complex than common diseases, meaning that there are a number of factors that combine to cause disease. In the case of P/P, while there seem to be genetic risk factors, how these contribute, singularly or in combination, and to what extent the environment (like diet and other conditions that are present) also contributes is not well understood. Somewhat fortuitously, complex diseases represent the next great frontier for drug developers. Having tapped into the ‘simpler’ diseases, making great strides in treatment of conditions like high cholesterol, these ‘low-hanging fruit’, as drug-makers like to call them, have been consumed. It is truly a time of paradigm-shifting mentality among drug makers.

That said, the costs of developing new medicines is extremely high, so companies must make their choices wisely. If we were to calculate the amount that pharmaceutical and biotechnology companies spend on research and development yearly and compare that to the number of drugs that are approved for clinical use by the FDA each year, the cost per successful drug is a staggering $1.2 billion. It’s not difficult to imagine, then, why companies aimed at developing new drugs are most interested in those that can recoup these huge costs – for instance, by developing drugs for very common conditions and risk factors such as diabetes and high cholesterol. As well, given the complex nature of rare diseases, they are not necessarily among the ‘low-hanging fruit’ that some diseases represent.

To incentivize companies to prioritize new drugs for rare conditions, they may apply for orphan drug status through the FDA, a result of passage of the Orphan Drug Act (ODA) of 1983. With this status, a drug receives seven years of market exclusivity. Market exclusivity is particularly appealing to companies developing drugs because the seven-year exclusivity period differentiates...
be able to encourage or provide research funding. Each year we participate in a legislative conference with the American Academy of Dermatology and the Coalition of Skin Diseases designed to advocate for favorable government policies that affect our patients.

A key issue is ending the government sequestration so that funding for medical research can resume. Finding cures and treatments for diseases like pemphigus and pemphigoid still requires primary and medical research to be realized. Under the Sequestration and current budget caps, the National Institute of Health research budget was cut by $1.7 billion and has scheduled another round of cuts in 2014.

Another important issue affecting many in our growing family patient community is access to specialists who treat our diseases and that accept Medicare. The specialists patients see are reimbursed through Medicare using a formula called the Sustainable Growth Rate (SGR), but their rate of reimbursement has not changed in over 15 years while demands and costs have increased.

Unfortunately, this has caused many experts in the field of blistering diseases to stop accepting Medicare patients altogether, harming our access to these much needed physicians.

Earlier this year, the IPPF joined other patient groups whose key priority was to advocate for enactment of H.R. 460, the “Patients’ Access to Treatments Act” sponsored by Rep. David McKinley (R-WV) and Rep. Lois Capps (D-CA). Commercial health insurers charge fixed co-pays for different drugs in different tiers with generics (Tier I), name brands (Tier II), and off-formulary brand medications (Tier III) with co-pays being set at $10/$20/$25.

However, some insurers are now moving vital medications (mostly biologicals like rituximab) into specialty tiers, this “fourth tier (Tier IV) is now commonly requiring patients to pay a percentage of the actual cost of these drugs. By moving these medications into the higher tiers, patients may be required to pay up to 33% more, costing hundreds - if not thousands - of dollars per month for a single medication. H.R. 460 would limit cost-sharing requirements in specialty drug tiers, and help make medically necessary treatment more accessible to patients with pemphigus and pemphigoid.

For the IPPF to achieve our mission and vision, we must continually strive to advocate on your behalf. However, we can’t do it without your involvement. I urge everyone in our community and networks to contact their local Congressional Representative and ask them to end the Sequester immediately, vote to repeal the current Sustainable Growth Rate (SGR), and support H.R. 460, Patients Access to Treatments Act. I know that at times you feel alone and are only one voice but together our voices can be heard and the IPPF is here to lead the way!

Marc Yale is a Pemphigoid patient living in Ventura, California. He has been a Certified Peer Health Coach with the IPPF since 2008 and he advocates for our patient community both on the State and Federal levels. Marc has contributed regularly the Quarterly in his column “Coaches Corner”. Marc can be reached at marc@pemphigus.org
Hypnosis and Stress

What they are and how they coexist

Janet Segall, CHt
IPPF Founder and PV Patient

People often have a difficult time understanding what hypnosis and hypnotherapy are and what their purpose might be. If you’ve ever been to a fair and a hypnotist asks someone to “cluck like a chicken,” and they do, the individual clucking knows exactly what he/she is doing. They may not care that they look silly because they are so relaxed from the hypnosis.

If you notice, there is usually always someone who won’t perform - these actions indicate that a person cannot do anything against their nature. In a less public setting, the practice of hypnotherapy is a valuable and positive method of helping people cope with many different and difficult issues.

Hypnosis is the process a hypnotherapist uses to help a patient find answers to issues that they are having trouble controlling. But what is hypnosis?

Most agree that it is a naturally altered state of consciousness. As defined by Gil Boyne, one of the leaders in hypnotherapy, it is “an extraordinary quality of mental, physical and emotional relaxation.” Many studies have shown that a person in hypnosis may show psychological and physiological changes that can be beneficial.

We all experience a form of hypnosis when we find ourselves “lost in the moment.” If you’re driving down the road listening to the radio and you notice that you’ve gone three exits without even realizing it - that is a form of hypnosis. Or, if you’re on your computer and in such a deep state of concentration that you don’t even hear the noises around you - that, too, is a form of hypnosis. What a hypnotherapist does is take you into that natural state of intense concentration and relaxation.

What is Stress? Stress is something we all deal with on a daily basis. Stress can be a good for alerting us to dangers. A rush of adrenaline can give you amazing strength and can help get you through physical and emotional challenges. If you diagnosed with a life-threatening disease like pemphigus or pemphigoid, stress levels may increase substantially, and for a sustained period of time. The issues that confront us can be overwhelming. Not only are we dealing with the illness itself, but the issues that come with it.

How can I live successfully with the drugs which can in themselves increase my stress levels? How is this affecting my family? Will I have the financial resources needed?

A hypnotherapist takes you into that natural state of intense concentration and relaxation.

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How can I live successfully with the drugs which can in themselves increase my stress levels? How is this affecting my family? Will I have the financial resources needed?

All these issues elevate our stress levels substantially. But what does that mean physically? Stress over a lengthy period can raise blood pressure, cause irritability, cause our thoughts to race, and many other problems. Many of us turn to drug therapy - both prescription or non-prescription to reduce the symptoms, while some of us look for alternative methods to augment drug therapy - these alternative methods include acupuncture, yoga, exercise, meditation and hypnosis.

What does hypnosis do that the other alternative stress reducing methods don’t? If you find the right hypnotherapist, someone you trust, you use your mind, your imagination, and your trust that the person you are working with can help you alter any negative thoughts or habits that plague you. The techniques the hypnotherapist uses are proactive approaches, meaning that you follow the sugges-
tions of the therapist and use your subconscious to perceive your issues in a different way.

There are definitely good and bad hypnotherapists, and there are places to go to find one – the American Society of Clinical Hypnosis (www.asch.net) is an example of one. But often as with a traditional therapist, you use your instincts in your initial interview to know whether that person is right for you.

I became interested in hypnosis many years ago. Since pemphigus and pemphigoid are autoimmune diseases (diseases of the self), I thought if I could learn all that I could about pemphigus and how the disease worked, maybe I could “talk myself out of it.” Unfortunately, my situation precluded me from furthering my quest. However, I learned to meditate, which helped with the side effects of prednisone. A 30mg dose every day for 3 years worked well and put me in remission.

At this point, I was able to put the theory that I could control my own body on hold. Some years later, when the disease returned, I again started thinking whether hypnosis could help. I searched the Internet looking for any literature on the subject and came across a small study that was performed by Dr. Francisco Tausch at Johns Hopkins University, on hypnosis and psoriasis.

I invited Dr. Tausch to speak at the 2005 IPPF Annual Meeting in Arlington, Virginia, on this subject because his research indicated that hypnosis might be helpful in treating psoriasis. Regrettably, his work on the possible connection was not yet complete. Could hypnosis help with pemphigus and pemphigoid? That is an unanswered question. However, from my two years preparing for my certification, and from my practice of hypnotherapy, I have learned for myself and from several people I’ve worked with that it reduces stress levels. This can open up one’s ability to look at life in a different way. I’ve been in remission – no drugs - from PV for 12 years but I have a high anti-Dsg3 titer count, making me very susceptible to lesions. Hypnosis has helped me reduce my stress so that I can notice my triggers if I get an oral lesion (which I do from time to time). As with any case study, it is not clear if the hypnosis has helped me to be successful in remission and to have a minimal, manageable number of lesions, but I believe that the power of hypnosis has allowed me to take some control over my body.

Because doctors often cannot spend a lot of time with an individual patient, the emotional component to treatment (their bedside manner) is often minimal. Hypnotherapy can be an extremely helpful factor in the emotional recovery of people with illnesses. When we are under stress because of an illness, our perspectives change. We tend to view things differently – whether positive or negative. We notice changes in our bodies we might not have noticed otherwise. What hypnosis can do with stress (and also pain) is to reduce its intensity and often change our perceptions of our feelings.

Could hypnosis help with pemphigus and pemphigoid?

We often tend to ignore our emotional needs when faced with disease. We hide our feelings making them less important than our physical state. As humans, we are all physical, emotional and spiritual beings. The only way to really bring health and well-being in a time of crisis is to acknowledge when dealing with illness, we must deal with the whole person.

References
Webmd.com

Janet Segall is the IPPF’s Founder and worked as Executive Director until 2008. She is a Certified Hypnotherapist and Health Coach. She is also Founder of Small Steps Counseling Services, a non-profit organization focusing on alternative therapies for wellness. She can be reached at (916) 420-1928, or by email at janetsegall@smallstepscounseling.org
fers from laws applicable to other drugs in that it does not begin until the drug is approved by the FDA approval.

The ODA is considered a resounding success. Since its inception, there have been more than 400 medicines approved for a total of 447 orphan diseases. As well, there are hundreds of new medicines in development, including an impressive list available in the PhRMA 2013 report (phrma.org/sites/default/files/pdf/Rare_Diseases_2013.pdf).

While not all of the 452 orphan drugs in development will be approved for patient use, this is certainly a lot of activity. A search of the list included within the PhRMA report, as well as a search of clinicaltrials.gov (that lists all clinical trials in progress), shows a handful of drugs in testing for conditions related to or directed at P/P.

There are 18 new orphan drugs in phase I-III trials (there are three phases of clinical trials and drugs must pass all of them, indicating reasonable levels of safety and meaningful efficacy-effectiveness in treating the condition) that are indicated for autoimmune disorders.

New drugs are not the only source of treatment for disease. Another source is to use an existing drug, developed for another condition, for a different indication. Such is the case with Rituxan® (rituximab), which was originally developed for Non-Hodgkin’s lymphoma. In that disease, B cells of the immune system bearing a marker called CD20 (thus the name CD20+ B cells) have gone awry.

Since P/P shares this hallmark, Rituxan® has been successfully used ‘off-label’ for P/P. It is an antibody-based drug, which requires it to be injected into the patient. In general, any drug that acts as a suppressor of the immune system (immunosuppressant) is a potential candidate for treating a range of auto-immune conditions, including P/P. CellCept® (mycophenolate mofetil), another immune system suppressor that was developed for transplant patients to help prevent the body’s rejection of the ‘foreign’ organ, has recently been approved for use in P/P.

Besides the high cost of developing new drugs, companies that seek treatments for orphan diseases face difficulty in finding enough patients to participate. Indeed, patients tend to be dispersed geographically and may include small children. Physicians and patients who are interested in participating in trials or gaining more information should visit clinicaltrials.org.

Within the P/P community, the IPPF is also a great resource for learning about clinical trials. Members of our medical advisory board serve as investigators on trials and being in our patient database could lead to a company reaching out to you about participating in a trial.

For instance, among the new drugs aimed at treating P/P, drug-maker Novartis is studying VAY736, an antibody-based drug aimed at another B cell marker called BAFF-R. The study is in a very early stage and should be recruiting patients soon.

The time is ripe for development of new drugs for complex orphan diseases. The surge in new medicines in the first 30 years since the ODA should accelerate as less ‘low-hanging fruit’ exist for companies developing new drugs.

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.
ly participating in some way - ANY way - there are many who would love to see you get involved. You do not have to dive into the deep end.

Start small, get your feet wet and move forward at a pace that is comfortable for you. Ask for help, guidance and advice along the way.

Consider sharing part of your journey with others in the P/P community. Maybe you...

- know of an informative article we can use in the Quarterly?
- would like to contribute a personal story that inspires others?
- are available for an interview for an article?
- can reach out to a newly diagnosed patient to lend an ear and encouragement?
- have advice for the newly diagnosed we can share on a broader scale?

Because of the support in our growing community, health coaches, webinars and annual patient meetings, you will meet people who can help you learn new positive coping strategies. These new tools will allow you to continue your own movement, becoming more and more resilient along the way. You will internalize the newer and more positive coping mechanisms, and hopefully leave behind older, strategies that are no longer working.

The point is that you WILL find yourself feeling and presenting yourself differently in this world. When you calmly and rationally respond to someone in a new way (rather than reacting), your response may even change how the other person responds to you - and others - in the future. You will gain momentum and move forward in your personal journey.

As I write this column, it is a typical colorful Pittsburgh Fall. Some trees are still green, some have lost their leaves and are bare, and others are continuing to change colors and are absolutely glorious.

Practicing mindfulness and being “in the moment” allows one to just watch and enjoy nature with a combination of awe and appreciation. I’m not a personal fan of cold weather and bare trees, I know we will have winter wonderlands soon, with freshly fallen glistening snow - on the ground and on the trees.

Everyone’s personal journey moves forward and changes just as the seasons change and cycle.

During your life journeys there are choices to make and different roads which can be taken. You can take the road most often taken or take the one not usually taken – neither is correct or incorrect. Just remember that there are always choices. Also try to remember that road that seems most “safe” may not be and may not help move you forward. Everyone makes mistakes, because humans are not perfect. Mistakes help people learn. Moving out of your comfort zone is not easy; it is a choice, and if you choose to stay on the same seemingly “safe” road, that is also a choice. Please let this last point sink in. DOING NOTHING IS A CHOICE.

Yes, life is a journey, but as you travel through, remember this quote: “What lies behind us and what lies before us are tiny matters compared to what lies within us” (Ralph Waldo Emerson). If you are reading this article and have gotten this far, look within yourself for that extra strength that may seem to be eluding you; it doesn’t always come from others. Maybe you just need to look a bit harder within. And, do not be afraid to ask for help.

Happy holidays. Try to start a new tradition this year. Tis the season to give - not just money, but of yourself. It will make your own personal journey more interesting and also sweeter, and by reaching out to others you will be making a far more important and satisfying contribution.

“What lies behind us and what lies before us are tiny matters compared to what lies within us.”
- Ralph Waldo Emerson

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.
Chicago is one of the world's most visited cities. A little known fact about Chicago: the word that most frequently follows the city's name is “famous.” Chicago's famous deep dish pizza. Chicago's famous Museum of Science and Industry. Chicago's famous nightlife. Chicago's famous skyline. Chicago's famous '85 Bears...and the billy-goat-cursed Cubs. Chicago's famous mob history. Or is that infamous? No matter what, Chicago has something for everyone!

Patients, caregivers, and physicians are invited to join us as we celebrate friendship and fellowship at the DoubleTree by Hilton on Chicago's famous Magnificent Mile. Guests at the hotel enjoy a discounted single King (or double Queen) room rate of $149 per night +$20 per additional adult (regularly $209-$229/night), $13 self-parking during the day and $35 overnight (regularly $50/night), and complimentary in-room WiFi Internet access (regularly $10/day). That's a total savings of $181 for a two-day stay!

This year at the 17th Annual Patient Conference we are introducing a format to allow time at the conference AND an opportunity to enjoy this great city. We begin Friday, April 25, 2014 with registration and introductory sessions, followed by our Welcome Reception. On Saturday, April 26, 2014, will be the general session ending around 1:00 pm. This will give attendees time to enjoy some of the area's famous pizza, sandwiches, and attractions -- all within minutes of the hotel. Come back later that evening for our 20th Anniversary & Awards Dinner. Join us for cocktails, food, entertainment, and Casino Night with great prizes and all proceeds benefiting the IPPF's Patient Support programs. On Sunday, April 27, 2013, there will be some general session talks with several interactive and informative workshops and Q&A with the speakers.

As always, the IPPF Board of Directors and Peer Health Coaches will be on hand, as will members of the IPPF Medical Advisory Board and local and global experts on pemphigus and pemphigoid. Dr. Ani Sinha and his team from the University of Buffalo will be on hand for the seventh consecutive year collecting blood samples from patients (and family members) for research.

Complete Conference Package - $200 per person
Meeting Only: $125 per person
20th Anniversary & Awards Dinner Only: $125 each

Tickets at the door are $200 per person for the conference, and $150 per person for dinner. We will accept cash, check, or credit card.

The actual cost per person is over $600, but you can join the fun for a fraction of that thanks to our Event Sponsors! Make sure to stop by their tables and thank them for their generosity and services to the pemphigus and pemphigoid community!

Register today at www.pemphigus.org/2014conference or by sending payment and completed registration form on the next page.

The past two conferences nearly sold out! Don’t miss this spectacular IPPF event as we celebrate our 20th Anniversary!
2014 Patient Conference Registration Form  
April 25-27, 2014  
Chicago, Illinois

Print Name (as you want it to appear on your name badge)  Organization/Employer Name (Corporate Sponsors Only)

Mailing Address - Street  □ Home  □ Work

City  State/Province  Zip/Postal Code  Country (other than US)

Daytime Phone:  □ Home  □ Work  □ Cell ( )

Email:  □ Home  □ Work

A portion of your registration may be tax-deductible. Please consult with your tax professional.

CASINO NIGHT GAMES ARE FOR ENTERTAINMENT PURPOSES ONLY.

Patient Conference Registration Fees

I WANT IT ALL! Complete Conference Package: $200.00 per person
Enjoy the conference from start to finish with a seat at THE best Saturday night event in town! You will be registered for Friday's introductory sessions and Welcome Reception; Saturday's sessions and 20th Anniversary & Awards Dinner (Casino Night with entertainment and prizes); and Sunday's sessions and workshops. Also includes light breakfast on Saturday and Sunday, all breaks, and any conference materials.

Conference Registration Only: $125.00 per person
You will be registered for all plenary sessions and workshops, Friday's Welcome Reception, Saturday's sessions, Sunday's sessions and workshops. Also includes light breakfast on Saturday and Sunday, all breaks, and any conference materials.

20th Anniversary & Awards Dinner Only: $125.00 per person
Can't make the meeting but still want to enjoy great food, friends, and fun? Join us at our 20th Anniversary and Awards Dinner (Casino Night with entertainment and prizes). Roll the dice, spin the wheel, or double down with proceeds benefiting the IPPF's Patient Support programs.

Scholarship Donation. Please help someone else attend this year's conference. $

Tax-Free Donation. Help support current and future programs and research. $

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□ Check/Money Order made payable in U.S. funds to IPPF

□ VISA  □ MasterCard  VISA/MC # __ __ __ __ - __ __ __ __ - __ __ __ __ - __ __ __ __

Exp. Date: __ __ / __ __  Security Code: __ __ __

Billing Address (if different from above): ___________________________________________________________

Signature: ________________________________________ Indicates you agree to have your card charged.

HOW TO REGISTER

1. Online: www.pemphigus.org/2014conference
2. Phone: (855) 4PEMPHIGUS (855-473-6744)
3. Contact your Peer Health Coach
4. Mail this completed form with payment to:
   IPPF 2014 Patient Conference
   1331 Garden Highway #100
   Sacramento CA 95833

Registration cannot be processed without payment. Payment must be in US funds. All cancellations must be received in writing or by email to info@pemphigus.org. For cancellations postmarked on or prior to March 14, 2014, we will refund registration costs less $25 administrative fee. Due to the contractual agreements such as food, beverage and material costs, cancellations postmarked between April 15 and April 10, 2014 may be refunded up to 50% of the registration fees. We may be unable to make refunds after April 11, 2014. We will gladly transfer your registration to another person (scholarship) or credit it as a donation.
2014 PATIENT CONFERENCE
APRIL 25-27, 2014
CHICAGO, ILLINOIS
DOUBLETREE MAGNIFICENT MILE

REGISTRATION OPENS JANUARY 2014

Join the IPPF leadership, staff, and PHCs as we host expert speakers, and patients and caregivers from around the world as the IPPF celebrates its 20th Anniversary in 2014!

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