THANK YOU!
2013 PATIENT CONFERENCE SPEAKERS

PETER MARINKOVICH
Stanford University

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Center for Blistering Diseases

JOHANNA BADGER
Stanford University

LAWRENCE CHAN
University of Illinois

FIRDAUS DABHAUR
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LAUREN GERSON
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CHARLES LIN
Stanford University

FRANCINA NUR
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ANIMESH SINAH
University at Buffalo

CHRISTOPHER TA
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TERRY WOLINSKY MCDONALD
Pittsburgh, PA

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Stanford University

VICTORIA WERTH
University of Pennsylvania

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TREATMENT BEYOND STEROIDS?
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International Pemphigus & Pemphigoid Foundation
Summer has always meant a lot to me. When I was a kid I played Little League baseball on the southern shores of Lake Michigan. One year, our team was a solid 0-10 (no wins, 10 losses). It was July 1 and it was my birthday. I was officially 11 and we were about to officially be 0-11. We were terrible!

My good friend Marty was pitching that day and things started looking up. As we entered the final inning, we were winning, but we were still three outs away from victory. We eventually won in “Bad News Bears” fashion...a little trickery, and a lot of luck. We still were the worst team in the league, but that day we were winners and I happily celebrated with my friends and family.

Recently I spent a weekend with my P/P friends and family at the 16th Annual Patient Conference in San Francisco. I am always amazed how much everyone seems to feel “at home” with one another...like a family!

I must thank our hosts, Dr. Peter Marinkovich and Bay Area Support Group Leader Prem Jain for having us in their home town. Other Conference Committee members included Dr. Terry Wolinsky McDonald (co-Chair/IPPF BOD), Greg Wright (IPPF BOD), Dr. Razzaque Ahmed (2012 Annual Meeting host), Nancy Stoeckel (KabaFusion and pemphigoid caregiver), Sonia Tramel (former IPPF BOD member), and Marc Yale (Peer Health Coach). The planning started in July 2012 and ended the day before the meeting started. This year’s event was a success for many reasons, but these people (and our event sponsors listed on the back cover) made it all happen. Thank you.

If you didn’t get a chance to join us (or if you did and just want a refresher), the audio has been transcribed for your reading pleasure! And PHC Jack Sherman has finished producing segments that will have the slides and audio combined – and be available as a DVD! You can find the 2013 Patient Conference materials at www.pemphigus.org.

A NEW LOOK! This also is the first newsletter being done by someone other than me since #39 back in 2004. Thank you to Special Projects Contributor Maeve Norton for her layout and graphic design skills. We look forward to this and future issues. Volunteerism is becoming more and more important in our operations as we remain lean, but still provide high-level programs and roll out new projects to benefit our community.

In celebrating our P/P family and friends, we extend our congratulations to Toby Speed who was married in May, and honor the memory of Bob Stillman who passed away in April. We are a small community – a family – and events like these affect all of us. We continue to share in the joys and sorrows of life together as one.

I hope you enjoy the Summer ahead with your family and friends. Remember, we’re here for you!
We had a great patient conference in San Francisco this past April. We introduced new content (e.g., talk on stress, Research and Development panel) and conducted the most streamlined conference in our history. Many thanks to all of our foundation staff, volunteers, and sponsors for putting on a great event! We look forward to a terrific conference in Chicago in 2014.

As the organization expands its activities by strengthening its patient support programs, and by pivoting into therapy access and reimbursement issues, as well as R&D and product development, volunteerism will become critical. For small organizations like ours, volunteers are a driving force. Our patients give us inspiration, and our volunteers give us propulsion. I ask you now to think about how you can contribute to the foundation.

We have created different types of volunteer positions to match people's interests and lifestyle preferences. You also can rotate through different positions. Anyone can contribute - not just patients, but also caregivers, friends, anyone that feels strongly about helping patients with rare/neglected diseases, wants to give back with their time and expertise, and wants to help grow a small organization to deliver greater impact.

We are looking to fill positions on the CEO's Executive Board ("CEO's senior staff"), Special Projects Contributors, and General Volunteers. Serving in one of these roles could position someone for greater leadership opportunities in the Foundation.

Please contact us if you would like to volunteer, or even to just brainstorm what opportunities exist to best utilize your talents and expertise. If you have a skill or an interest, we will find something that works for you. (See page 5 for a description of volunteer roles).

Someone from the Red Cross recently told me that around 95% of their "workforce" consists of volunteers. We can do the same. Let's leverage the power of the IPPF community to catalyze positive change.
Volunteer Role Descriptions

CEO Executive Board

This person heads up a “department” or initiative under the CEO. Examples include managing our patient support programs, planning and running our annual meeting, editing our newsletter, running fundraising events, and developing an R&D strategy. Other areas include finance/accounting, collaborations, and project management. The commitment would be for one year or the duration of the initiative (whichever is shorter). We are open to ideas for new “departments” and initiatives, and want to tailor a position to an individual’s talents and interests. This role is good for people who are operationally oriented and want a significant role within the foundation.

Special Project Contributor

The Special Project Contributor (SPC) role provides a way for people who have special expertise, resources, and access to contribute to the organization in the frame of a short time commitment and specific scope. It allows individuals to make a substantive contribution that fits their interests and lifestyle. Example projects include: competitive landscape analysis, review of clinical guidelines, exploration of a specific clinical care question, legal analysis of a specific issue, building a data management platform for our patient registry, crafting a media strategy, helping set up and negotiate an external collaboration, developing a market access/reimbursement advocacy strategy, and setting up a fundraising initiative (e.g., a silent auction). This role is good for people that have a special expertise they would like to leverage in the context of a short project. SPCs are encouraged to propose their own projects as well.

General Volunteer

General volunteers can contribute across a wide range of initiatives and events. Example areas to contribute include website design, newsletter/media, printing, art design, annual meeting preparation and on-site help, event planning, accounting, and community fundraisers (e.g., 5K run). 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.

Current SPCs

Sonia Tramel (accounting/tax-prep), Maeve Norton (graphics and design), Michelle Atallah (research and development), and Lee Heins (patient support).
SEEING THINGS FROM A DIFFERENT PERSPECTIVE

Janet Segall
CHt, CHC
Founder IPPF

I remember one of the first calls I received was from a woman in Northern California. It was 1995 and the Foundation was just getting started. She had been diagnosed with PV 30 years earlier at the age of 19. Over the past 30 years she had nobody to talk to about her disease. Her husband didn’t want to talk about it. She didn’t want to burden her children with it. She felt alone. She was so happy when she found us and finally was able to lift her silence about the illness. And I heard many similar stories throughout the years.

Because these are rare diseases, finding information and support is difficult. Back in 1995, finding any information on pemphigus and pemphigoid was nearly impossible. You had only your doctor to rely on to know the answers, and many times the doctors didn’t know themselves.

Since the Internet became popular, access to information is easier, but it can be confusing to find the exact information you need. This is why the IPPF is so important. Besides giving patients correct information, it helps patients understand pertinent information; provides emotional support; and provides comfort - all of it from staff and many wonderful caring volunteers. Volunteers are a big the reason why the IPPF is still going strong after so many years.

Many of us have been in remission a long time – no disease and no drugs (or maybe just a small dose). We go about our daily business not wanting to think about the disease we’ve learned to live with. But there are many out there who are newly diagnosed, about to be diagnosed, or still dealing with issues associated with the diseases years after diagnosis. We can help. We can give people the support they need by volunteering for the IPPF. It is important for the IPPF and for the patients to be able to connect with those of us who have “been there, done that!” Staying connected to the IPPF and the patients is beneficial and means so much to so many.

We have an unusual perspective – we’ve been where they are. We know what works and what doesn’t. Even if we are all different and our level of disease activity not the exact same, there are experiences that we all have in common. Talking to someone in remission can be a blessing to people who need your help. With so few of us around, everyone can provide some level of expertise that will help someone get through a bad day, or a scary day, or a “hey, I had a great day today!”

One thing I’ve noticed about helping others, it helped me too. Even though I’m off all drugs, I still get an oral lesion from time to time. I think most of us in remission probably do. For just a moment, I worry if the PV is coming back, but I go about my business for the day and put it out of my mind. When I’m helping others, the last thing I think about is my PV. For some reason, helping someone else deal helps me put it into perspective.

I know everyone cannot volunteer … but we all can support the IPPF in one way or another. It’s an important organization if you or someone you know has the disease, or you just want to make sure others do not have to suffer alone with pemphigus or pemphigoid.

The IPPF is important for all of us. Volunteer if you can. Donate when you can.

We need to make sure the IPPF is here today, tomorrow and in the future until we have a cure.
What it Means to be a Citizen of the IPPF

From his talk given at the 2013 Patient Conference in San Francisco

Dr. Badri Rengarajan
IPPF President

It’s a pleasure to be here with you all today, and an honor to take the helm, along with our CEO Will Zrnchik, at what I believe is an inflection point in the Foundation’s growth. I wanted to share some sentiments that I hope will guide and enrich your experience this weekend.

For some time now, I have been thinking about what it means to be a citizen of the IPPF. I am not a patient. I am a family member. I am involved with this Foundation because I care. I don’t want anyone to go through the pain and suffering I saw my mother go through.

I know from seeing her and other patients that physical discomfort and pain are significant, but even worse is the loss of confidence that comes from feeling like you are a shadow of your former self, feeling alone and uncertain, and finding that even people who you thought could help – like your family doctor -- may not be familiar with the disease. This foundation can help. Remember the people sitting next to you: they can help. And when you feel less than yourself, don’t give in.

Once again look around: these people can help. The foundation can give you a community of patients, caregivers, doctors and researchers. As you get control of physical pain and psychological stress, you will see a light at the end of the tunnel and eventually make it outside, and although the world will be different than what

CONTINUED ON PAGE 12...

Dr. Badri Rengarajan
IPPF President
According to a recent scientific article published by Dr. Sergei Grando (IPPF Medical Advisory Board Vice Chairperson) and some of his colleagues from the University of California, Irvine, “The ultimate goal of pemphigus research is to develop an effective treatment modality that would allow patients to achieve and maintain clinical remission without the need for systemic corticosteroids.” This represents the next great horizon in treating the disease since the use of corticosteroids was implemented in the 1950s. Prior to that, patients were not expected to live more than five years after the onset of their disease. So we’ve come a long way but goals like that of the Grando research group are lofty indeed.

To begin to develop new treatment strategies for any disease, it is important to better understand the underlying biology that causes the disease and that is associated with disease physiology. Targeting pathways with drugs is the ultimate goal and it is all the better if the drugs used are specific to these pathways as this will limit potential side-effects associated with their use. This would seem to exclude the use of steroids such as those that are a standard of treatment currently. In their current work, the groups of Dr. Grando and Dr. Ping Wang (Journal of Biological Chemistry, http://www.jbc.org/cgi/doi/10.1074/jbc.M113.472100) examine the effects of antibodies (IgGs) known to be present in PV patients and find that they deleteriously affect specific functions of the mitochondria of skin cells (keratinocytes). The mitochondria are the compartments within cells where all of the energy, in
Somewhere along the line, the general public came to believe that doctors are all-knowing they are always right, never wrong. Many of us know doctors who also seem to believe this. Clearly -- and thankfully -- not all doctors feel this way.

However, we are putting our lives in their hands, and what could be more important than that? I would venture to say that most people, especially those with rare, chronic illnesses have doctors that they absolutely love and have total confidence in their expertise. Meanwhile, others are not so lucky and believe they have limited physician choices with certain illnesses.

As a patient whose initial diagnosis took nearly a year to get right, and who seen all kinds of "specialists," I found many of the professionals to be nice people. However, many were clueless even after a biopsy was done. I think some of them felt badly about it. Still, they just kept sending me to other specialists, mostly oral, but no one seemed at all clued in.

As a professional myself, I spent years working with, or parallel to, many other professional doctors who also were stymied. I was never told that my symptoms were psychosomatic or psychological by those who knew me. Because my mouth and throat were practically raw, I could not eat or drink many things. I lost weight (maybe 13 pounds after a year which for me is a lot) and at least two physicians thought I had anorexia - even though it was crystal clear how difficult it was for me to eat and to swallow. I was particularly puzzled by dentists, oral surgeons, endodontists, periodontists and even oral pathologists who could not recognize what was happening in my mouth. Skin and blood were literally falling out and my mouth was horrible to look at -- a total disaster!

I was not just discouraged at appointments, but frustrated over the time it had taken me away from my livelihood. These specialists who did not know me seemed to think that I had an eating disorder. I quickly dispelled that notion, told them they would not be paid for wasting my time, and left quickly making sure to call my insurance company to stop any payments for services not provided. It was about the principle for me. I believe that a person cannot know everything -- I am the first to admit that.

I am thin by nature – so thin that the first time I was in the “normal” range was when I was giving birth. Still, with all the effort I put into keeping weight on, I kept losing weight. Is there anyone out there with these diseases who hasn’t gone through this? Even for those who are overweight to begin with, the initial weight loss with the oral symptoms has to be traumatic.

My primary care provider (PCP), an Internist, was someone I had known since we had been residents together at the hospital where we worked. We had worked well together and shared a mutual respect with a good relationship prior to all my "new" and "mysterious" symptoms. He had absolutely no idea what was going on, but never seemed to grasp the seriousness of my situation, or that it was
I was diagnosed with PV in April 2000. I didn’t know anyone else with this disease and I felt alone, but at least I was being treated by a great doctor in Houston, TX – Dr. Robert Jordon.

I started coming to the IPPF’s patient conferences in 2003. I have attended every year since, except for the 2009 meeting in Los Angeles due to surgery. People ask me why I keep coming back year after year, and the answer is simple: because I learn something new each year.

Where can I get the latest updates on PV and how it affects my body? The Patient Conference. And where can I find information on the medicines that are used to treat my illness, the side effects, and what I can do about them? The Patient Conference. And where am I able to sit around and have a conversation about these issues with another patient? Or a table full of patients? Or a room full of them? Yep, the Patient Conference!

I go so I can live a full life. Some of the doctors at the meetings do valuable research on pemphigus and pemphigoid, so they are very knowledgeable on how the diseases affect me and everyone else. THAT makes me feel comfortable knowing they know what they are talking about. The presentations are informative and get better each year.

But even more than just listening to them, I get a chance to ask these world-renowned expert doctors my specific questions and get answers I may not be able to get elsewhere. And patients get to take this invaluable knowledge back to their doctors and share it.

And I do more than just take away information; I try to encourage other patients. I tell them the pain they’re going through now will get better, the lesions will go away, and you will regain control of your life. I am living proof that things DO get better. I understand the pain and frustrations that come with these illnesses. New patients don’t, so that is why patients in remission or who have had the disease a long time should go to the Patient Conference: to help others. A patient can get sympathy anywhere; but empathy from people who really know what you’re going through? Only at the Patient Conference.

Lastly, I like the exciting cities where the Patient Conferences are held. Over the years, the members of the IPPF group – staff, board members, and other patients – have become like family. I look forward to seeing them each year and hearing about their lives and families. In essence, for me and others it is more than an annual Patient Conference, it’s an annual Family Reunion!

So my advice to everyone is pretty simple: keep a positive attitude, pray, and go to at least one Patient Conference.

I hope to see ya’ll in Chicago!
New Coaches
New Perspectives

Although everyday (whether I like it or not), I am reminded what it is like to live with pemphigus and pemphigoid, I am fortunate because I have the opportunity to share my story and build relationships.

Recently, the IPPF has welcomed two new Peer Health Coaches to our team, Mei Ling Moore (Los Angeles) and Gloria Gutierrez (Orlando). They both have been providing support for our community members for quite some time so it seemed only natural for them to volunteer as Peer Health Coaches. Both are compassionate listeners who actively participate on the IPPF website and Facebook page, communicate well with those that need support, provide relevant resources designed to improve patient/caregiver issues and make a difference in people’s lives by building long-lasting relationships.

I had the honor of seeing them in action recently at our annual Patient Conference in San Francisco and was amazed at how well they both provided confidence and hope to everyone they spoke with.

Please join me in welcoming Mei Ling and Gloria, and feel free to reach out to them for peer advice.

Remember, you always have a "Coach" in your corner!

Marc Yale
IPPF Senior Peer Health Coach
marc@pemphigus.org

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the form of ATP, is generated.

Protecting mitochondria, the authors believe, should help to alleviate the cell death that is associated with PV.

IgGs produced in PV cause keratinocytes to die due to their being “split” apart or detached from each other within the epithelial layers of the skin (fact check). However, the mechanisms by which IgGs cause this splitting and in fact, whether there are more than one type of IgG generated in PV has not been determined. Previous work from Dr. Grando’s group has contributed to a theory where various antibodies that bind to keratinocytes, including the well-described anti-desmoglein antibodies, work together to cause the cellular effects that lead to PV.

As well, previous work has implicated the mitochondria in PV. Indeed, the mitochondria that have been tested from lesions of PV patients are defective in many of their key functions. These include maintaining a balance of antioxidants and limiting the production of reactive oxygen species (ROS) that lead to untold cellular damage.

The current paper solidifies the model that multiple targets of keratinocytes (both on the surface – the desmogleins, and inside – the mitochondria) are at play in PV. As well, it suggests that multiple antibody types are involved in the end result – cell death. The antibodies that the authors focused on are called mitochondrial antibodies (MtAbs) because of their ability to enter keratinocytes and bind to mitochondrial proteins. MtAbs make up what may be the most important class of IgGs in PV patients. Removing MtAbs from the serum of PV patients makes the serum incapable of causing keratinocyte detachment. Serum is what remains of the blood after you remove all of the cells – including proteins, antibodies and small molecules from metabolism. The authors have now found that the IgGs from the serum of PV patients can cause the mitochondrial dysfunction seen in previous work.

These IgG mixtures, which contain the MtAbs, cause numerous changes in the vital functions of mitochondria. For instance, they saw an increase in the production of ROS from keratinocytes, a decline in ATP production, and changes in the mitochondrial membrane potential, a hallmark of the tidy cell death pathway called apoptosis. This is the first time scientists have shown such dramatic changes in mitochondrial functions with patient IgGs. Even more striking is that compounds that protect mitochondria could help the keratinocytes resist the adverse effects of the IgGs. These compounds, minocycline, nicotinamide (a well-known over-the-counter antioxidant supplement), and cyclosporine A have previously been used, often in combination, with beneficial effects on PV patients, but an understanding of why they are effective hasn't been clear until now.

Since these three mitochondria-protecting drugs are already in use in some PV patients, the authors argue that optimizing their use, by determining at what levels they need to be dosed in individual patients, for starters, should make them an ideal non-steroid treatment for PV.

I see all of the activities of the foundation coming down to four imperatives:

1. We are trying to improve a patient’s quality of life -- skin care, eye drops, puréed foods, emotional support.

2. We are trying to reduce the length of time it takes to diagnose patients. This comes from educating dentists, doctors and nurses.

3. If we can support research on disease flares, we might lay the groundwork for an academic institution or company to develop tests to predict emergence of flares. In fact, this may be a more pragmatic approach in the near term than going for a cure.

4. Ultimately we can support research and product development efforts that will someday
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CONTINUED ON PAGE 14...
The Sjögren's was diagnosed by a rheumatologist who specialized in lupus.

I told him I was either totally psychosomatic or that there was definitely something else going on. Fortunately he took appropriate action. That was a true blessing. I believe there are many physicians who really do listen to their patients and see “whole people” and not just symptoms or illnesses. These are the doctors I seek out – and one I try to be in my own psychology practice.

I left my original PCP shortly after the PV diagnosis. After a few other non-successful attempts to find the right care provider, I found one after changing insurance companies. I even found a gynecologist who actually knew the disease in the event it affected me below the belt. I'm happy with my current treatment team because we work well together as patient/physician. Some personalities just don't seem to work together. I have remained under the care of my rheumatologist for a number of years now and he has no problem making decisions with input from both me and an expert dermatologist.

We as patients are very fortunate that there are experts out there willing to give time and expertise. I never take this for granted, especially since I cannot take prednisone. If not for alternative systemic treatment only a few doctors believed in when I was diagnosed, I would not be here today. If not for the generous time of these experts talking long-distance with my local doctor (at no extra charge to me) and having a local doctor who was willing to ask for help, my life would have ended painfully more than 10 years ago.

It has not been an easy road, but I am determined and tenacious - which have served me well over the years. I have been very pleased with my PCP whom I have been seeing for a number of years now. She definitely "listens" and respects her patients.

Amazingly, about a month ago, totally out of the blue, I received a very nice letter from my original PCP whom I had not seen in almost 11 years. I knew he still practiced in the city, but our paths haven't crossed, except the sharing of a few patients who needed coordination of care. In his letter he made some small talk and also seemed to know how I was doing and about my other diagnosis. Out of sight but not out of mind! He let me know he believed I was a strong person and was sure I had put together a team of competent doc...
tors. Then, surprisingly, he basically let me know he felt he had "failed" me, but that he believed that his failure with me had helped him to improve his care with certain other patients. WOW! I was humbled and felt so empowered.

This letter was very refreshing and very reassuring to me. I have taken several opportunities to present continuing education on pemphigus to the local dental school. This letter has given me HOPE and REASSURANCE that our messages do get across. Yes, we all have the ability to strengthen awareness and to educate: It does not have to be to a massive audience, but every professional reached makes a difference.

As the Foundation moves forward with our Awareness Campaign, it is my most fervent hope that no matter how frustrated and angry you may get that each if you continue to teach and educate medical professionals about early diagnosis and treatments.

Just don't give up! That mindset leads to something called "learned helplessness" - which leads to a core belief system that no matter what you do, nothing will make any difference. This leads to major depression.

Keep going. Move forward. You can make a difference. All of us can! How awesome is that?

---continued from PSYCHOLOGICALLY SPEAKING, page 14

bring us to a cure and make this picture disappear. The foundation is about these four imperatives. Help us fulfill them for yourself and for all those around you.

If we come together and help each other, we can make an undeniably meaningful difference in patients’ lives. The foundation is a vehicle for your efforts. The foundation gives embodiment to our collective aspiration to help our patients and their families. I hope you will get involved.

My mother is a success story. Though she has to be vigilant, she is living a good life. So should all of our patients. For those recently diagnosed, stay strong – you will get through this. For those in remission, lend a helping hand to those still dealing with active disease.

For all of you, think about how you can catalyze positive change for the entire community. As you approach this weekend, ask yourself what you can do to be a true citizen of the IPPF. I wish you all the very best.

---continued from CITIZEN OF THE IPPF, page 12

The IPPF commitment and dedication to patient care is commendable!

KabaFusion is an innovative National Home Infusion company with Headquarters located near Los Angeles, California. The CEO & Founder, Dr. Sohail Masood and the Leadership team have a 20 year history in the management of patients receiving both acute and chronic infusion therapies. KabaFusion specializes in Immune globulin therapy for patients seeking the comfort and safe administration of therapy in their home. It has a premier system of managing patients by coordinating intake, clinical and pharmacy services, home infusion with nurses present for the entire therapy and outcomes, not equaled by other IVIG providers.

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