The Clinics Releases Two Books on Autoimmune Blistering Diseases

Over the years there have been very few textbooks devoted to autoimmune blistering diseases (AIBD), such as Pemphigus and Pemphigoid (P/P). While some focus on the pathology, and others on management, there has yet to be an up-to-date, all inclusive text reference. Until now.

A recent, two-part work includes articles written in the preceding 6-12 months by respected leaders in AIBD -- many of whom are on the IPPF Medical Advisory Board (MAB).

The work was divided into two parts with a leading AIBD clinician writing about the clinical aspects of a specific disease, followed by a leading investigator writing on the pathogenesis of that particular subtype of that disease.

Because there is so much information on AIBD, the first issue focuses on clinical features, diagnostic testing and pathogenesis; and clinical disease management in the second.

Autoimmune Blistering Diseases: Part 1 (Volume 29, Number 4, July 2011) has an article explaining the key diagnostic immunofluorescence testing needed for AIBD from the leading European team, led by Helmut Hintner and Gabi Pohla Gubo (Austria). This is followed by articles on Pemphigus Vulgaris, covering clinical features by Dedee Murrell’s Australian team.

In the Genetics of Pemphigus, Animesh Sinha’s team in Buffalo, continued on page 8...
Dear friends,

As the year comes to an end, we can all be thankful for our blessings and look forward to another year in which each of us renews our commitment as individuals and a community held by a common bond to make a difference. Each act of kindness, no matter how quiet or discreet, contributes to improving the lives of people we know and love as well as individuals we may never meet – and together we make the world a better place.

As a Foundation, we have a great deal to be thankful for receiving -- and proud of achieving. Through the amazing effort of a group of talented and caring Peer Health Coaches, IPPF leadership staff, and volunteers ... WE CONTINUE TO MAKE A DIFFERENCE!

We pushed the edge of knowledge forward and disseminated the latest information in illness mechanisms and treatment directions. With the collective effort of our entire community, we have grown the P/P Patient Registry to an unprecedented level! This will empower us in 2012 for the first time to study illness trends and treatment outcomes in a large number of people with a rare disease. This registry is positioning us to ask critical questions and learn from them. It is also attracting the attention of scientists who want to develop better treatments. It will also enable us to more effectively advocate for improved healthcare policy and resources. We have just completed a key study addressing current diagnostic trends and with this data will be developing a campaign to effectively increase awareness and reduce diagnostic delays. These represent just a few examples of our collective success this year, and there are many more examples as well. Thank you all for your contribution to these successes, and we look forward to very productive 2012.

As the years change, the IPPF is also experiencing changes in its leadership. This change is a natural process and presents opportunity for renewed purpose, fresh perspective and new ideas. Molly Stuart has resigned as our CEO after a very productive tenure leading our organization in a spectacular fashion. Molly was a fantastic change agent for the IPPF and helped us sustain and expand the vision of our Founder, Janet Segall. Molly has left an indelible mark on the IPPF and we will be forever grateful for her skill, compassion and dedication; we wish her success and happiness in her future endeavors. Dr. Amit Pandya has resigned from our Medical Advisory Board after years of tireless and selfless effort on behalf of our patient community. We will miss Dr. Pandya’s great enthusiasm and keen intellect as well as his warm and caring personality… we wish him continued success in all he pursues.

We have also seen recent change in our Board of Directors leadership as the Honorable Janice Taylor has stepped down after many years of dedication and effort on our leadership team; we are so very grateful to Janice for her service and wish her health and happiness. And we welcome William Gerstner to our Board of Directors. Bill comes to us with a spectacular background in organizational effectiveness and leadership, and like many of you, was drawn to the Foundation because of a close friend diagnosed with Pemphigus. Bill has a keen sense of community and volunteerism, and has already made tremendous contributions in his first month on our BOD.

And we all welcome Will Zrnchik, a familiar, talented and beloved member of our IPPF leadership team who is now serving as our Interim CEO. We are grateful to Will for his willingness to step up, keep us going, and bring his fresh perspective and leadership style to the IPPF. Our BOD and Will are committed to a careful assessment of the IPPFs future directions and workforce/leadership needs... we welcome your input and look forward to sharing our plans as they are developed.

I wish you all a very joyous holiday season, and a very healthy and personally rewarding new year. And I ask that each of you make an effort to support this wonderful Foundation. We rely on your talent and spirit, and we need every patient and caregiver to support the Foundation. Please make a personal commitment to the Foundation and support our efforts on your behalf -- both with your ideas and acts, as well as a financial donation.

Every person can give something. If we each accept that opportunity together, we will accomplish so much and continue to improve the lives of individuals affected by this illness -- and ultimately find a cure!

With very warm wishes and fondly,

David A. Sirois, DMD, PhD
President, IPPF Board of Directors
dave@pemphigus.org

From the President

International Pemphigus & Pemphigoid Foundation
Greetings everyone!

Every year we take a moment to look back and reflect on what we have accomplished in order to better define where we are going. This is a great tool for personal growth, and in business it is an absolute necessity.

In 2011, the IPPF made over 6,500 patient-related phone calls, emails, and mailings helping 1,425 individuals! We saw over 81,000 unique visitors visit our website! On November 1, 2011 alone, 20,500 pageviews were recorded! And the IPPF sends and receives an average of 7,000 emails a month! As you can see...we're quite busy!

I am proud to announce the IPPF was recognized for outstanding creative achievement by the Association of Marketing and Communications Professionals. The AMCP awarded the IPPF with a 2011 MarCom Platinum Award for our 2010 Annual Meeting Program in the Design/Print (Program Guide) category, and a 2011 MarCom Gold Award for our IPPF Registry Package in the Marketing/Promotion Campaign/Research Survey category. With over 6,000 entries from around the world, including Aflac, Amway, Arthritis Foundation, Booz Allen Hamilton, Hilton Hotels, Lockheed Martin, and the US Air Force -- the IPPF proudly ranks up near the top!

We were also busy spreading awareness, advocating on our patient’s behalf, and learning how to better function as a Foundation. IPPF representatives attended or presented at the American Academy of Dermatology Association and Coalition of Skin Diseases’ Capital Hill Day, Centric Health Resources’ Ultra Orphan Forum, Drug Information Association’s Annual Meeting, FasterCures’ Partnering for Cures Conference, and dozens of webinars and teleconferences. These events help keep the IPPF up to date on issues that affect P/P patients, as well as put the IPPF out in front of decision makers and supporters, so we can continue as a thriving advocacy, awareness, and support organization.

And in 2012 the IPPF will do even more! As Dave mentioned, our Diagnostic Pathways & Awareness Project is going great! The Health Management Program will have online home helps to Centric Health Resources. The new HMP will drastically reduce delays in enrollment, feedback, and scheduling while providing you - the patients - with valuable tools to improve your quality of life! The American Academy of Dermatology Annual Meeting is in San Diego March 16-20, 2012, and the IPPF will be on hand at the Coalition of Skin Diseases booth to educate attendees on our disease. Our 15th Annual Patient/Doctor Meeting will be held in Boston, MA, May 18-20, 2012 at the Hyatt Harborside Hotel. Carolyn and Raymond Blain will once again host the PEM Friends 2012 Away Weekend in June. And that’s just in the first half of the year!

On a final note, don’t forget to support the IPPF this holiday season with a tax-free contribution! There is still time to make your 2011 donation by visiting us online at www.pemphigus.org/donate or calling (916) 922-1298 x1003. Every donation helps the IPPF help you -- and others around the top.

My family and I wish you all a safe and happy Holiday Season!
O
ver the years many people have quoted the phrase that “change is the only constant.” Al-
bert Einstein thought outside the box that great sci-
entists had, for so many years, believed was an abso-
lute. He had to go to extraordinary lengths to prove E=MC2. Nowadays, a compliment on one’s intelli-
gence often includes the word “Einstein.” His name is synonymous with genius. I wonder how the young Einstein, didn’t think in terms of speed of light, but rather visualized what he thought it would be like to ride on a ray of light, would react to this. He would probably be amused after his own uphill battle.

The fact is that most people don’t like change and will often go to great lengths to keep the status quo. However, change is a constant, which is why human beings need positive coping skills in their repertoire to be successful in making inevitable transitions.

With the proper tools, people become more re-
silient; without them, people develop Adjustment Disorders, which can be debilitating. Adjustment Disorders come in all sizes and shapes. They can af-
fect our mood and create depression, anxiety and behavioral changes making the mind-body connec-
tion prominent.

Adjustment Disorders can be either temporary or chronic. Temporary ones can be difficult but recov-
ery can be relatively quick. Chronic Adjustment Dis-
orders can be life-long and can take over a person’s way of being, causing them to sort of “drop out” of life and exist. And there are others who continue on, but feel under tremendous stress ALL THE TIME.

A number of successful people who are not chron-
ically ill (either physically or psychologically) have asked me why so many people today are on psycho-
tropic medications. It’s an insightful question. Pre-
viously reserved for people with major psychologi-
cal disorders like Schizophrenia or Bipolar Disorder, today many psychotropic medications are commonly used.

At first I thought maybe psychiatrists and psychol-
ogists had just gotten better at diagnosis. I have now realized that the world we live in is moving at a much faster pace, and human beings’ brains are probably not wired (from a neuropsychological point of view) for all the current technology and speed in our lives.

Meditation does help – as does slow, diaphrag-
matic breathing, relaxation exercises, imagery, yo-
oga, running, walking, and other physical exercis-
es previously discussed in this column. These are all coping tools which allow all people to bring life down a few notches. Having that tool belt, filled with tools for change and transition, has become necessary just for people to feel like they don’t have to constantly tread water or swim furiously against the current in order to stay afloat.

And, this is what’s necessary now for everyone - especially those living in this fast paced and of-
ten confusing world with serious chronic illnesses like P/P! This may be a good time to take a deep breath and just be grateful to be alive. Always try to inhale through the nose. Exhaling does not have to be painfully slow, but rather rhythmic and deep. Try to get the air into the belly, likening it to filling a balloon. The tools are not difficult and can be re-
hearsed anywhere.

The key is to recognize when difficult or new sit-
tuations are affecting you, and then being prepared. The more you learn from these expected and unex-
pected changes, the more resilient you will become. It’s when situations arise and we use the same skills

Continued on page 10...
Make Your Donation Even More Valuable

Did you know your donation could be matched dollar for dollar by your employer? And did you know that some companies match two or three times your donated amount?

The procedures vary with each company, and usually employees must submit their donation through their employer, or the employer provides a form the donor sends in with their donation. Either way, the IPPF will verify our nonprofit status with your company and complete any necessary paperwork required.

The matching gift program began in the 1950’s when General Electric’s chairman wanted to encourage employee giving to colleges and universities. Since then, companies like Adobe, Apple, Microsoft, Motorola, and others have added matching gift programs to encourage their employee’s donations to charitable organizations like the IPPF.

For more information on the IPPF donation programs, please call (916) 922-1298 x1003, or email donate@pemphigus.org.

15,000 Companies Match Gifts... Does Yours?

Contact your Human Resources Manager and ask if they have a Matching Gift Program you can participate in.

Pemphigus Pathfinders Raise $22,000 in Canada

Congratulations to the Canadian Pemphigus & Pemphigoid Foundation’s Pemphigus Pathfinders! The group raised $22,000 during the Scotiabank Charity Run in October 2011.

Victoria Carlan got the CP-PF officially started in 2008 after the IPPF held it’s Annual Meeting in Toronto. Led by Chairman of the Board Dan Goodwill (also a member of the IPPF BOD) and newly appointed Executive Director Cindy Anthony, the CP-PF continues to grow as a valued source for patients and caregivers in Canada.

For more information, please visit www.pemphigus.ca.
Partnering for Cures brought together over 800 philanthropists and investors; medical research foundations and institutes, biotechnology and pharmaceutical companies, academic investigators, and policy makers with the ultimate goal of **decreasing the time and cost it takes to deliver new or re-purposed therapies to patients.**

During the opening keynote, University of San Francisco Chancellor Susan Desmond-Hellman asked, "How can social media change the world, and not health?" Traditional scientists and researchers are landlocked by intellectual property (IP) restrictions and often do not share information with other scientists. Using a networked concept can break down the secrecy barrier making critical information available for collaborative study that could lead to new or re-purposed treatments.

These were recurring topics during the conference: IP, collaboration, and re-purposing. The IPPF uses social tools to connect with patients and gather data faster and securely. The IPPF website, Facebook page, Twitter feed, Health Management Program, Patient Registry, and the recent Awareness Project are ways the IPPF has connected with patients and gathered essential research data at reasonable costs and with manageable time lines.

And these methods are fast becoming ways government and researchers WANT to interact and collaborate. The challenges will be removing intellectual property (IP) concerns so information can be freely shared and mined for research. "The key to accelerating research for any patients...is to have efficient access to well-characterized patient populations willing to be part of research," said Jamie Heywood, Co-founder and Chairman of PatientsLikeMe. "It’s terrifying to think you’re alone and manage your rare illness with a doctor who might not have ever seen another patient like you." And for Pemphigus and Pemphigoid patients, this is a common occurrence.

The IPPF programs allow us to make a difference. As stakeholders, we all have a vested interest in that success. If you are currently enrolled in the Health Management Program, thank you! If you have submitted your data to the P/P Registry, even better! If you haven’t...now is the perfect time.

Partnering for a cure involves all of us! The sooner we can support research, the sooner we eliminate delays in diagnosis, increase therapy availability, and keep treatment cost affordable.

**Do YOUR part today!**

www.pemphigus.org/hmp

Our NEW online portal is coming soon! Ask your Peer Health Coach about it today! Don't have a PHC? Get yours at www.pemphigus.org/hmp!
Don’t be a medical victim
It’s good to speak up during a doctor visit if you don’t think you made yourself clear because remember, too many mistakes are made in a busy hospital.

Read more at http://wp.me/p1w91A-10o

Annual family health premiums soar 9% over last year
Annual premium costs for employer-sponsored family health coverage grew far faster than workers’ wages and general inflation in 2011, putting even more pressure on workers and employers in a sluggish economy.

Read more at http://wp.me/p1w91A-XV

Doctors are not always right
Medical schools are starting to train doctors to be more in tune with patients. And patients are starting to train themselves to be less intimidated by doctors. The federal Agency for Healthcare Research and Quality has begun a new campaign to encourage patients to ask more pertinent questions and to prod doctors to elicit more relevant answers.

Read more at http://wp.me/p1w91A-Xu

Mental health in patients with Pemphigus
People know that everyday life is already challenging enough, but toss in Pemphigus and Pemphigoid and things can overwhelm even the best of us.

Read more at http://wp.me/p1w91A-13F

The IPPF website offers patient and caregiver support and information in one location.
Creating a FREE account shares access to additional resources like the Patient Forums. Visit today at:

www.pemphigus.org
...continued from AIBD, page 1

N.Y., believe newer candidate gene and whole-genome approaches are needed to discover the full spectrum of PV genetic risk elements.

In the Pemphigus Foliaceous section, clinical features were presented by Luis Diaz (UNC-Chapel Hill), and the pathogenesis of endemic PF, fogo selvagem, by Dr. Diaz’s Brazilian collaborator, Valeria Aoki. The clinical features of Paraneoplastic Pemphigus (PNP) are covered, but little is known about its pathogenesis, yet there is hope this gap will be filled in coming years.

Bullous Pemphigoid (BP) clinical features are discussed by Luca Borradori (Switzerland) who says BP diagnosis relies on immunopathologic exams including direct immunofluorescence microscopy and detection of serum autoantibodies by indirect immunofluorescence microscopy or BP180-ELISA.

The pathogenesis of bullous Pemphigoid is discussed by Hiroshi Shimizu (Japan) who states BP is the most common autoimmune blistering disease.

Dedee Murrell’s Australian team presents on the clinical features of Pemphigoid Gestationes.

Kim Yancey’s team from the University of Texas Southwestern discussed Mucous Membrane Pemphigoid (MMP), a disease in which he and his group made seminal discoveries. Yancey mentions scarring and loss of function can be prevented by early diagnosis and appropriate interventions.

Hair and nails expert, Antonella Tosti (University of Miami) states nail abnormalities can even precede skin findings in PV. She said nail lesions often relapse just before generalized disease recurrence, and severe nail changes are often associated with extensive and severe disease. She cited a report associating excessively bleeding nails with difficult PV cases, and nail scarring is a rare complication of BP. Regardless, fingernails are more commonly affected.

In Autoimmune Blistering Diseases: Part II - Diagnosis and Management (Volume 29, Number 4, October 2011), the drugs commonly used to treat AIBD are discussed.

- Stefan Beissert (Germany) suggested long-term follow-up studies (>3 years) are needed for azathioprine, and patients undergoing treatment should avoid long-term exposure to the sun and have a skin exam twice a year
- Daniel Mimouni (Israel) discussed how mycophenolate mofetil combined with corticosteroids, and even azathioprine has positive benefits for PNP patients
- Vicky Werth (University of Pennsylvania) suggested before taking dapsone, the patient should be screened for glucose-6-phosphate dehydrogenase deficiency to reduce risks
- Pascal Joly (France) suggested that rituximab should be considered if two or more traditional systemic therapies have failed
- Amit Pandya (University of Texas Southwestern) recommends nonstick dressings, tube gauze, and rolled bandages to correctly dress P/P wounds
- Tess McPherson and Vanessa Venning (Oxford, England) have a chapter devoted to AIBD and Pregnancy. They mention poor disease control during pregnancy causes more problems than the medications themselves do

Overall, these two issues will undoubtedly serve as educational resources for dermatologists, clinicians, scientists, patients, and caregivers alike. Understanding what is already known about a disease helps teach and clinical practice, better research and provide current and relevant information based on recent studies and research. For more information, please visit www.theclinics.com.
PEM Friends Gather in London For November Lunch
by Clare Trott, PEM Friends

It’s 4pm on Friday, November 4th, and the final four are just leaving Peter Jones restaurant to make their way to various parts of the UK, including the North of Scotland! It has been a fantastic four hours for the PEM Friends (www.pemfriends.co.uk) who were able to make the trip to London for our lunch. There were 15 of us in total, some arriving early and only able to manage a short time with us, while others arrived later.

The buzz of conversation was loud and clear and everyone managed to catch a conversation or two with everyone else, sometimes one-to-one or else in small groups. We learn so much from each other and it’s a great opportunity to compare notes. The “uncommon bond” really is so strong. New members are warmly welcomed and our long-standing members feel it’s like coming home to the family. It is so good to catch-up with each other and see the progress we make on our Pemphigus or Pemphigoid journeys.

We welcomed six new members of PEM Friends to the event and everyone took away with them valuable information, hope and a sense of no longer being alone. It is good to know we travel the road together.

As the Christmas decorations sparkled, so did PEM Friends, amid the fun and laughter that was heard. The event truly was a rewarding lunch. After all lunch was four hours!

“It was wonderful and inspiring to meet all of you. I look forward to the next get together” (Julie)

P.S. We never quite found the perfect moment for a full group photo (apologies to those who are not in shot!)
that no longer seem to be working – over and over – that is most detrimental.

I have trained myself to breathe so slowly that when attending seminars and partnered with other professionals where we are asked to utilize the deep breathing, I have to pre-warn my partner to not get nervous when I slow down my breathing even further. It can be scary for some. It is just part of my everyday arsenal, and I don’t think about it: if a situation arises, I automatically slow down even more. When I was younger and healthier I preferred a good fast walk, but my general health does not afford me that luxury any more. That’s okay since I have been able to add these tools to my arsenal.

While P/P patients may deal with physical and emotional problems and changes on a daily basis, some are more successful than others with the changes and transitions of their illnesses and of daily life. The more successful people likely have a tool belt full of positive coping strategies that still work; some of the strategies may be old, but many are likelier newer. Of course, having a strong primary support system does help. The IPPF PHC’s (Peer Health Coaches) can answer questions and help in both concrete and emotional ways. Patient family, friends, colleagues and caregivers make a difference as well. The Health Management Program, Email Discussion Group, and website are also invaluable.

In life in general, but especially in times of transition, it is critical to be aware of our weaknesses, but focusing on those will keep us stuck, as well using coping mechanisms which no longer work. What moves us forward and allows us to keep up and succeed is our ability to hone personal strengths and build/refine positive coping tools.

Our coping mechanisms and transition strategies will only continue to grow. In these turbulent times, with global wars, economic instability, a health care system in need of healing itself, we need more tools to cope with transitions.

The IPPF has had a number of recent changes and continues to morph, transition and move forward in ways we could not have imagined. What allows this smooth transition is our ability to learn from the past, and trust in the amazing people who serve on our MAB, BOD and staff, all focused on our commitment to the patients. Our IPPF family has grown, not just in number, but in the loyalty, dedication and sincere contributions of our staff and patients. Transitions are part of the IPPF’s past, present and without a doubt, our future.

I say, “Bring on the transitions!” We can handle them.

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Dr. Terry Wolinsky-McDonald is a licensed clinical psychologist in the Pittsburgh, Pa. area. She is a member of the IPPF Board of Directors and frequent contributor to the Quarterly. Her articles focus on the psychological aspects of living with P/P in patients, caregivers, and family members.
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May 18-20, 2012 • Boston, MA

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HOW TO REGISTER
1. Register Online: www.pemphigus.org/annualmeeting
2. Call our offices: (916) 922-1298 x1003
3. Contact your Peer Health Coach
4. Mail this completed form with payment to:
IPPF AM Registration, 2701 Cottage Way #16, Sacramento CA 95825

Registration cannot be processed without payment. Payment must be in US funds. All cancellations must be received in writing. For cancellations postmarked on or prior to April 20, 2012, we will refund registration costs less $25 administrative fee. Cancellations postmarked between April 20 and May 11, 2012 may be refunded up to 50% of the registration fees. We may be unable to make refunds after May 11, 2012 due to food, beverage and material costs. We will gladly transfer your fees to another person as a scholarship, or credit you with a tax-free donation.

Annual Meeting Registration Fees

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<td>Registration Fee Includes attendance for all three days, materials, food/beverage during meeting times, Friday’s Welcome Reception, Lunch on Saturday, and Saturday Evening’s Gala Dinner Celebration! Subject to change without notice.</td>
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| Caregiver Badge (one may only be purchased with each paid Regular Registration)
  Name to appear on caregiver badge: ____________________________________________ | $75  | *$100 at the event |

Scholarship Donation. Please help someone else attend this year’s meeting.
Tax-Free Donation. Help support current and future programs and research.

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Thanks to the patients of Boston, commemorative shirts will be provided to paid attendees. Please indicate the quantity of sizes you desire. ___ XXL ___ XL ___ L ___ M ___ S ___ XS (MUST equal number of paid registrations; sizes may be substituted based on availability)

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BOSTON: 2012

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