MEET THE NEW CEO

The IPPF Board of Directors is pleased to announce the hiring of our new CEO, Molly Stuart.

See page 3

DR. ROBERT JORDON HONORED BY IPPF

Immunofluorescence pioneer and IPPF MAB Member honored for his contributions.

See Page 4

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THANK YOU to our 2007 Donors & Sponsors

The IPPF is root-tootin’ and rarin’ to go! Dallas, Texas and the University of Texas Southwestern Medical Center are hosting the 11th Annual Patient/Doctor Meeting. Why Dallas? From cowboys driving cattle across the plains to Cowboys driving towards the end zone, Dallas has been a rich part of America for over 150 years.

Dr. Amit Pandya, IPPF Medical Advisory Board and Professor of Dermatology at UTSW, is the primary clinical coordinator for this year’s event. Local experts Dr. Pandya and Dr. Kim Yancey will be joined by Dr. Animesh Sinha, Dr. David Sirois, Dr. Victoria Werth, and 10-time Annual Meeting speaker Dr. Grant Anhalt. Quarterly columnist, and member of the IPPF Board of Directors, Terry Wolinsky McDonald, PhD, will also be presenting.

If you have not been to one of our previous meetings, we invite you to come early on Saturday as our Patient Orientation and Information session with Dr. Grant Anhalt is casual and informative. On Saturday, presenters will discuss updates on research and clinical trials; drugs and their side effects; and the best way to live successfully with our disease. Sunday’s session will begin with a Q&A with the doctors, then a session for patients and caregivers. This allows us to candidly discuss how we feel about our medication (and our care), what choices we make to help ourselves live better with our disease, and how we can help each other.

The IPPF has blocked rooms at the Renaissance Dallas Hotel, 222 Stemmons Freeway (214) 631-2222. Our Friday night “get-together” reception, and Saturday night’s authentic Texas dinner buffet, are being held at the Renaissance. Room rates for the IPPF block are just $99 a night.

Visit the Southfork Ranch, home of the TV series “Dallas,” or the Book Depository Museum. Dallas is a beautiful city with something for everyone. This year it offers something more: fellowship and camaraderie for those living with pemphigus and pemphigoid. Come join us... you will be glad you did.
On behalf of the IPPF and its Board of Directors, Janet and I are very pleased to announce the appointment of Molly Stuart, JD as the Chief Executive Officer of the IPPF effective Monday February 18, 2008.

More than one year ago, the Board identified as a strategic priority the need to hire a CEO to add to the talent of our Foundation and join us in our efforts to expand the scope, impact and effectiveness of the IPPF. Following a recruitment effort this winter, we were very fortunate to identify Molly as just that talented individual.

Molly comes to us with years of experience in the business and non-profit consulting and leadership arena. In addition to her considerable management and leadership experience, she possesses a remarkable spirit, energy and humanism that will no doubt enhance our Foundation and reflect highly on our values and goals. Read more about Molly in her biographical sketch on page 3, and please make plans to join us for our Annual Meeting in Dallas April 5-6 where you can meet Molly and participate in several achievement celebrations of the Foundation!

On behalf of the IPPF and the BOD, I wish to thank Janet Segall for all she has been — and will continue to be — for our Foundation. Without Janet, there would be no Foundation. She created, nurtured, and led our Foundation to its prominence as THE advocacy group for patients with pemphigus and pemphigoid. And, for the past 2 years has served effectively and graciously as our Interim Executive Director.

Janet will now focus her energy on what she loves best: caring for people affected by pemphigus and pemphigoid. In her role as Director of Patient Services and Education, she will put her considerable talents and energy to work enhancing the support and education mission of the IPPF.

From the Top

David Sirois, DMD, PhD
President
Board of Directors

Janet D. Segall
Director of Patient Services and Education

2008 Dallas Agenda

On Saturday...
New Patient Orientation
Emerging Treatments
Patient Care Plan
Research and Progress
Risk for Relapse
Side Effects
Immunobullous Diseases
Oral Health
Living with Your Disease

On Saturday Night...
Celebration Dinner

On Sunday...
Q&A
Patient & Caregiver Support
BOD Elects New IPPF CEO

Molly Stuart brings with her a proven green thumb that grows flowers, as well as businesses, into things of beauty.

The Board welcomes Molly Stuart to the IPPF, please extend your greetings at the Annual meeting, or sooner. Molly was chosen by the Board for her depth of expertise in organizations moving through periods of great change and IPPF is certainly doing that! As part of our plans to increase patient services, medical resources and funding, the Board was interested in leading the organization to the next level with professional business expertise. Molly, a management consultant and professional negotiator, is certified in mediation and critical incident interventions. She holds an undergraduate degree in psychology and a law degree from the University of the Pacific, and is licensed by the State Bar of California.

After a period as a professor of law, Molly turned her attention to the practical application of leadership in supporting organizational development. She focuses on change leadership — managing turnarounds of organizations, preparing for acquisitions/mergers, or planning succession strategy. As a C-level executive Molly has led private sector firms, quasi-governmental organizations and international non-profits. Molly has received numerous awards for business improvement including recognition by the US SBA as an Entrepreneurial Leader and national recognition including the 2006 State Star for California leadership excellence.

Since 1987, Molly has lectured, advised and published extensively in areas of leadership, change, communication and business development across the country, including UC Davis Executive Leadership Academy, McGeorge School of Law, California Institute for Integral Studies and University of Tennessee. She has also authored articles in academic journals as well as popular publications.

Aside from her professional credentials and experience, Molly considers herself a gardener at heart, hosting many local fundraisers there; walks extensively with her dog, Jack; and volunteers as a trauma chaplain at local hospitals and crime and accident scenes, offering support to families in crisis.

Molly Stuart has spent most of her career helping others. Her travels have led her from California to the Midwest to the Southwest and back. Along the way, Molly has helped organizations realize their full potential and grow to new levels.

After settling the IPPF into offices that have a spot for her to sit down, Molly will focus her attention on growing support for the IPPF that will bloom into increased advocacy for healthcare policy, development of patient support and relationship building, and creating financial backing that will expand our ability to do both. Again, please join us in welcoming Molly.
IPPF Honors Dr. Bob Jordon

This year, the IPPF will be honoring Dr. Robert Jordon at the Annual Meeting’s Dinner, at the Renaissance Hotel, Dallas, TX, on April 5, 2008.

Dr. Jordon has been working at the University of Texas Medical School, Houston for the last 25 years, as Professor and Chairman of the Dermatology Department. He graduated from medical school in 1965 from State University of NY at Buffalo. While training in Dermatology at the Mayo Clinic, he earned his M.S. from the University of Minnesota, Minneapolis. Since then Dr. Jordon has made enormous contributions to the field of Dermatology. He has extensive memberships in many organizations and has received many honors and accolades, including being named to the “Who’s Who in America” listing. He has been on many editorial boards and review and advisory boards, including the IPPF’s Medical Advisory Board. He has coauthored many publications and written chapters for medical books. He has also authored several books on the subject of immunological bullous diseases.

Dr. Jordon could be considered “the father of Immuno Dermatology.” He and Dr. Ernest Beutner were the first to use a new technique called immunofluorescence to show that pemphigus and pemphigoid are autoimmune diseases that mediated by autoantibodies. This formed the basis of future knowledge of these diseases. His contributions have yet to be equaled by anyone else. His work and dedication to the field is the reason we are honoring him this year.

Clinical Trial Update: Dapsone

Recent study hints towards as a suitable alternative in pemphigus treatment

Medical Advisory Board member Victoria Werth, MD, recently headed up a study, “Multicenter Randomized, Double-blind, Placebo-Controlled, Clinical Trial of Dapsone as a Glucocorticoid-Sparing Agent in Maintenance-Phase Pemphigus Vulgaris.”

The objective of the study was to determine if dapsone, a drug in a family of drugs called anti-infectives which has been used to treat leprosy but with anti-inflammatory properties, would work as a glucocorticoid-sparing agent in the maintenance phase of pemphigus vulgaris. This trial was designed as a double-blind, placebo-controlled study with a crossover arm for those with failed treatment.

From June 1997 to January 2003, nineteen subjects were enrolled among five centers, with nine randomly receiving dapsone and ten given the placebo. The study included patients between the ages of 18 and 80 who were unable to reduce steroids successfully two times, within a 30 day period of stable steroid dosing. All patients were on steroids and/or an immunosuppressive.

Patients with PV are often on maintenance doses of steroids for long periods of time. Because steroids can cause serious side effects such as diabetes, osteoporosis, cataracts, etc., the goal is to find a good steroid-sparing adjunctive medication.

Often efforts to reduce steroid doses lead to flares. Dapsone, considered to be less problematic for patients as a steroid-sparing drug, has been successfully used in the past in a number of individual case studies. This was the first double-blind effort to prove that dapsone is an effective agent for patients with otherwise controlled disease.

The study design was to give a maximum of 200 mg/d of dapsone, making sure that hemoglobin levels did not fall to a clinically meaningful level. The blood counts were monitored monthly once the maximum dose of dapsone was reached. Steroid doses were tapered either on a daily or every other day protocol. Flares were treated with increases in prednisone.

Participating patients had to have chronic disease in a maintenance stage, have failed two attempts to taper steroids, and be on a stable dose of steroids for the previous 30 days. Patients were assessed monthly for 1 year after reaching the highest dapsone dose. Success was measured by steroid doses being tapered to 7.5 mg/d and by a patient who maintained a dose of 7.5 mg/d for more than 30 days.

Of the nine patients on dapsone, five were able to reduce their steroid dose to less than 7.5 mg/d, whereas only three of the ten did in the placebo group. The differences were not statistically significant, potentially related to the low number of patients recruited to the trial. However, there was some evidence that dapsone may be a suitable alternative treatment in some cases.
AAD Meets in San Antonio: IPPF Receives Gold Triangle Award

by Janet Segall

This year, the AAD was held in San Antonio, TX, January 31 - February 5, 2008. On February 1, the IPPF received the American Academy of Dermatology’s (AAD) Gold Triangle Award for its excellence in website development. Janet Segall, Director of Patient Services and Education, accepted the award on behalf of the IPPF. Also attending the luncheon were IPPF Medical Advisory Board members Dr. Jean-Claude Bystryn, Dr. Amit Pandya, Dr. John Stanley, and Dr. Luis Diaz.

Since pemphigus and pemphigoid are so rare, it is often difficult for patients to get the help they need. Patients have felt alone and depressed with their disease. The IPPF has brought together patients from around the world to discuss every aspect of their disease. It has given patients hope for a better life. We provide discussion forums, a checklist for patients to ask questions of their physicians, and the most up-to-date and credible information on the diseases approved by leaders in the field.

Although we primarily target the pemphigus/pemphigoid community, we also bring information about our disease to the general public and the dermatology community. The IPPF website has been revolutionary in helping patients learn how to live with pemphigus/pemphigoid.

What is the Gold Triangle Award?
The American Academy of Dermatology’s Gold Triangle Awards recognize and honor health organizations, health individuals, public service accomplishments, and industry and media efforts that further the understanding of dermatologic issues and encourage healthy behaviors in the care of skin, hair and nails.

From the Webmaster...

In the coming year we are hoping to further enhance the community experience on the IPPF website. I would like to develop a better method of sharing “individual space” with others in the pemphigus and pemphigoid community.

One thought is to develop a social network independent of the IPPF main site similar to MySpace™ and Facebook™. This would be limited to our patient base just like now, only with the features many people already use on other sites. But that is just a thought. Other ideas include electronic versions of the newsletter, video and audio chat, and more.

But for now let’s just keep the online community strong! Questions? Comments? Suggestions? Please do not hesitate to email me at will@pemphigus.org.

Above - Dr. Jean-Claude Bystryn, Ms. Janet Segall and Dr. Amit Pandya pose with the Foundation’s most recent award, the AAD Gold Triangle given to the IPPF for our website and dedication to patients and caregivers.

Below - Dr. Deedee Murrell and Ms. Janet Segall take a moment to pose for the camera at the Foundation’s booth. In addition to her work in Australia with patients and the Australian Blistering Disease Foundation, Dr. Murrell is currently working with Dr. Victoria Werth (University of Pennsylvania) on the Pemphigus Outcome Measures clinical trial.
MAB Adds Two European Pemphigus Experts

We would like to welcome Professor Pascal Joly and Professor Michael Hertl to our Medical Advisory Board. These two renowned physicians bring to the IPPF many years of experience in auto-immune diseases, namely pemphigus and pemphigoid.

**Professor Pascal Joly**
Since 2004, Prof. Joly has been the Head of the Dermatology Department at Rouen University Hospital, Rouen, France. He has been the President of the French Society for Dermatological Research and is a member of the European Society for Dermatological Research, as well as its President. He has been a member of the European Academy of Dermatology and Venereology (EADV) since 2002, and is now President of the 2008 Paris EADV Congress.

Prof. Joly’s main interests are immunodermatology and oncodermatology, including basic research, clinical, and therapeutic trials on autoimmune bullous skin diseases, drug-induced reactions, malignant melanoma and cutaneous lymphoma.

He has been the President of the French Study Group on Autoimmune Blistering Diseases for 10 years. This group includes 26 Dermatologic centers in France. It has conducted 6 of the 9 randomized therapeutic trials published in international literature on autoimmune bullous skin diseases. He is currently conducting 2 major therapeutic trials on bullous pemphigoid and pemphigus with this group.

He is also conducting studies on the pathogenesis and new therapeutic options in patients with drug-induced eruption with eosinophilia and systemic symptoms (DRESS), one of the most severe drug induced reactions.

Finally, he has been participating for 10 years in the French Study Group on Cutaneous Lymphomas, one of the most active groups in the world on this topic. He has been involved in all the numerous studies performed by this group that have been published in many journals of Dermatology.

He has authored more than 150 international publications, been a reviewer for many Dermatological journals and is an Expert for AFSAPPS, the French National Drug Agency.

Recently, with Professor Joly’s involvement, the IPPF became the catalyst for a clinical meeting on pemphigus and pemphigoid to be held in conjunction with the upcoming Paris EADV meeting in September.

**Professor Michael Hertl**
Also joining our Medical Advisory Board is Professor Michael Hertl, Marburg, Germany. Dr. Hertl is Professor and Chairman, Dept. of Dermatology, Phillips-University Marburg, Marburg, Germany. He received his medical degree in Germany and received a fellowship in Immunodermatology in the U.S. at Case Western Reserve University in Cleveland, Ohio. He worked at the National Cancer Institute, NIH, Bethesda MD, under the direction of Dr. Stephen Katz for 2 years. He then returned to Germany to work in several different universities where he is currently Professor and Chairman in Marburg.

Prof. Hertl’s special clinical interests revolve around numerous areas of skin diseases including autoimmune diseases of the skin, core and clinical research in pemphigus and other autoimmune disorders. He has received several honors and awards through his career, from the Dermatology Research Training Award, American Academy of Dermatology, to the Niilo-Illja-Richter Prize of the German Society for Autoimmune Diseases, Kiel.

We are very pleased to have Professors Joly and Hertl’s expertise as part of our MAB.
Diagnosis and Mortality Issues: FEAR OF DYING

Overcoming it is easier said than done

Mortality issues are at the very core of the “human” condition. In Ernest Beck’s book, Denial of Death, the author asserts that as infants we believe we are like little gods until we realize that we have waste products which need to be disposed of (think Freud’s Anal Stage and the second stage of Eric Erikson’s stages of human development through the life span). For Beck, this realization is what guides our lives; we know we are not immortal and that we will eventually die. This is true for all humans, but once diagnosed with a potentially fatal and chronic illness such as pemphigus or pemphigoid, for which there is no cure, it is totally normal and expected for a person to have many more questions and to become more concerned. These questions and concerns can be very specific but also extremely frightening. They can either paralyze the patient or move the patient to more action. These actions may be both positive and forward moving or negative and detrimental.

Fear of death and/or not having a “normal” life (whatever that may mean for an individual) emerge and affect the patient/person’s long held beliefs. Piaget wrote about “schema” and how people perceive things in ways which make sense. These schemas begin early in life and to a large extent are based on early life experiences and how they are interpreted. As people age it is easier to alter something new to fit into an already existing schema than to alter the schema to fit the new information. This is why so many people continue to make the same mistakes, and why it is so difficult to learn new ways of assimilating information. How can patients expect a life threatening diagnosis to not wreak havoc with their brains and thought processes?

In the DSM IV (The Diagnostic and Statistical Manual of the American Psychiatric Association) there are specific diagnoses regarding mood and anxiety disorders which are specifically related to _____________ (to be filled in with the person’s physical illness). Adjustment disorders can also be expected during times of stress and change.

In addition to severity of symptoms, there are also major differences based on the age and support systems of the person when diagnosed. Imagine being a young child or teenager, versus someone older and with perhaps half or more of their life expectancy behind them? While everyone knows that death is inevitable, they also hope to live good, long and productive lives. Diagnosis of serious chronic illnesses will change people’s lives in various ways.

For example, in brief, when children receive such a diagnosis they may feel less “normal” compared to their contemporaries, but with good support they often have more resilience. They may be likely to compensate more positively over time, although the severity and course of the illness and treatments will be variable. Please remember that none of these examples are absolute or invariable. Teenagers and young adults who are diagnosed will usually have more difficulty accepting that the planned course of their lives will likely change forever. They feel attacked just as they are attempting to start their adult lives and figure out who they are. Those diagnosed in their 30’s and 40’s are likely to be more upwardly mobile, possibly at or near the top of their game, with relationships and families to contend with, in addition to work issues. Being diagnosed after age 50 usually means children are older or grown, so there may be less concern there, but this age group is still trying to move forward in life and often have workplace and relationship issues in addition to possibly also being caregivers for older parents and sandwiched between two generations. If diagnosed later in life, many people already have other ailments which go along with the aging process. Health and life style will be critical in adjustment. Again, adequate support systems

As people age, it is easier to alter something new to fit into an already existing schema than to alter the schema to fit the new information.

continued on page 12…
Siri Lowe, the Founder and head of the PV Network, the first support network for pemphigus patients in the United Kingdom, submitted an article to the British Medical Journal on her thoughts and journey living with pemphigus vulgaris. The article was accepted for publication and appeared in the December 21st edition of the Journal.

She broke the article up into sections: “The Early Years” where she discussed how difficult the diagnosis of pemphigus vulgaris was for her, and how she had to adapt to the ongoing side effects of the drugs, the emotional toll from the pain she felt from lesions, and the difficulty of the damage the side effects had on her body.

The second section, “The People Around Me,” focused on her supportive environment of friends that helped get her through the tough times and helped her put the disease in perspective. She talked about how grateful she was for her contact with the IPPF realizing that she could start a similar group and help people in the UK.

A third section, “What Works Well,” focused on how important the alliance between her and her full medical team (dermatological, internal medicine and surgical) should be; and how important it was to keep the same team to ensure continuity of care.

In the fourth section, “What Works Less Well,” Siri talked about the emotional toll this diagnosis can take on someone. She discussed the problems she had while having surgery for breast cancer with a hospital staff that didn’t understand pemphigus or how proper bandaging could make an enormous difference in care. She stressed the confusion of language, for example, using improperly defined words like remission showing how detrimental that can be to care. A major problem was how often doctors do not or will not consider the importance of a patient’s knowledge about their own body and disease process.

Included in the article was “A Doctor’s Perspective,” written by one of Siri’s doctors confirming her fortitude in dealing with this very difficult disease.

Siri was hoping that after the article was written, dermatologists would take the opportunity to use this information to show that patients as well as doctors are very worried about the way that dermatology hospital services are changing because of the complicated policy divisions in England. Her doctor, Anthony du Vivier, consultant dermatologist at King’s College Hospital, London stated, “The lesson that was reinforced to me about caring for her, and for most patients with serious skin disorders, is how essential resourced specialist dermatology services are.”

Summer is right around the corner and with that comes CAMP WONDER 2008. Please help us to send as many children as we can to camp this year.

The Children’s Skin Disease Foundation is now accepting applications for Camp Wonder 2008, an incredible camping experience being offered to children with skin disease, ages 7-16, at no cost to the organization, child or family. The week offers the opportunity to participate in exciting activities, form lasting friendships and ultimately develop a stronger sense of self-esteem while under the careful and loving supervision of an excellent medical staff and counselors. The session will be from June 22 - June 28, 2008 in Livermore, CA.

For more information please contact Christine Tenconi at 925-351-7225 or by e-mail: ctenconi@hotmail.com.
Applications accepted on a first come basis.
Local Support Groups in the News

Local Support Groups Do Make a Difference!
Contact us for information about finding or starting a group in your area at info@pemphigus.org

Boston SG
Returns to Yankee Dental Congress for Second Straight Year

Each year, the Massachusetts Dental Society, in cooperation with the dental societies of Connecticut, Maine, New Hampshire, Rhode Island, and Vermont, hosts the Yankee Dental Congress (YDC). The YDC is the fifth largest dental conference in the US and the largest in New England. The 2008 conference was held January 31 thru February 3, 2008, at Boston’s new conference center bringing together over 28,000 dental professionals.

The exhibit floor showcased innovative products, technology and services, as well as the finest educational courses in dentistry. Courses are offered not only to dentists, but to students, hygienists, technicians and other office staff.

Last year, for the first time, the Boston Support Group (BSG) provided an educational table at YDC with a PowerPoint® display. This year, the BSG set up a planning committee to plan its table. Thanks to the generosity of Burt Gordon, they were lent a pop-up display giving them the opportunity to display a large poster: but what to put on it?

This is where Alan Papert says that the result of six years of thinking about how to get our message across – and three graduate PR courses (which as a senior citizen he attended at Boston University) – suddenly paid off. One goal was to understand the audience and the other was to use as few words as possible. The result, with valuable input from Dr. David Sirois and Will Zrchnik, is the poster in the middle of the display. This had pictures of what the dental professionals should look for in the early stages of the diseases and a warning of how the condition can quickly deteriorate if the cause is not recognized.

Thus, it was much easier to guide passers-by into a discussion of pemphigus and pemphigoid and encourage them to take our hand-outs (of which we very nearly ran out). Contact was made with several vendors which, hopefully, will lead to cooperation in the future. For instance, Alan talked to the software manager at Kodak® in charge of their tooth mapping software. He is going to consider putting in an alert to hygienists to be suspicious of persistent blisters or lesions with a link to IPPF. Hopefully, someone will contact Janet or Dr. Sirois for advice on this.

Our profound thanks to the volunteers who manned our table: Carol Fischman, Ellen Levine, Alan Papert, Gloria Papert, Barbara Revkin, Aimee Reveno, Hayat Weiss, and Karen Zallen. Karen also designed our banner to emphasize that we were not a commercial organization, but members of a support group.

The BSG hopes that next year we will be able to use a standard display that can be used by other support groups at other dental conferences.
A sliced **Carrot** looks like the human eye. The pupil, iris and radiating lines look just like the human eye... and YES, science now shows that carrots greatly enhance blood flow to, and function of, the eyes.

A **Tomato** has four chambers and is red. The heart is red and has four chambers. All of the research shows tomatoes are indeed pure heart and blood food.

**Grapes** hang in a cluster that has the shape of the heart. Each grape looks like a blood cell and all of the research today shows that grapes are also profound heart and blood vitalizing food.

A **Walnut** looks like a little brain, a left and right hemisphere, upper cerebrum and lower cerebellum. Even the wrinkles or folds on the nut are just like the neo-cortex. We now know that walnuts help develop over 3 dozen neuron-transmitters for brain function.

**Kidney Beans** actually heal and help maintain kidney function and yes, they look exactly like the human kidneys.

**Celery, Bok Choy, Rhubarb,** and more, look just like bones. These foods specifically target bone strength. Bones are 23% calcium and these foods are 23% calcium. If you don’t have enough sodium in your diet the body pulls it from the bones, making them weak. These foods replenish the skeletal needs of the body.

**Eggplant, Avocados and Pears** target the health and function of the womb and cervix of the female – they look just like these organs. Today’s research shows that when a woman eats 1 avocado a week, it balances hormones, sheds unwanted birth weight and prevents cervical cancers. And how profound is this – It takes exactly 9 months to grow an avocado from blossom to ripened fruit! There are over 14,000 photolytic chemical constituents of nutrition in each one of these foods (modern science has only studied and named about 141 of them).

**Figs** are full of seeds and hang in twos when they grow. Figs increase the motility of male sperm, and increase the numbers of sperm as well, to overcome male sterility.

**Sweet Potatoes** look like the pancreas and actually balance the glycemic index of diabetics.

**Olives** assist the health and function of the ovaries.

**Grapefruits, Oranges and other Citrus** fruits look just like the mammary glands of the female and actually assist the health of the breasts and the movement of lymph in and out of the breasts.

**Onions** look like body cells. Today’s research shows that onions help clear waste materials from all of the body cells. They even produce tears which wash the epithelial layers of the eyes.

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This was received from a member of our Email Discussion Group. Originally titled, "God’s Pharmacy" by its anonymous author, it can be found online in many versions.

The IPPF cannot speak to its credibility or endorse it; however it is interesting and fun, so enjoy!
# IPPF MEETING REGISTRATION FORM

**NAME:** ____________________________________________ **AGE:** ___________

**ADDRESS** ____________________________________________  **# of Previous Conferences Attended** __________

**CITY** ____________________________________________  **STATE** __________  **POSTAL CODE** _________

**COUNTRY (if other than United States)** ____________________________________________  **PHONE** __________

**EMAIL** ____________________________________________

☐ I require special assistance (please attach a written description for all persons with special needs)

Please list names and ages of other guests who are attending.

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*Cancellations may be not refundable after April 2, 2008.*

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**All registrations must be received by the IPPF no later than MARCH 31, 2008**

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☐ I request scholarship assistance. Please call me immediately and accept this donation to help defray costs.

**GRAND TOTAL** $

Check ☐ Money Order ☐ Visa ☐ Master Card ☐

Card #: _____________________________ - _____________________________ - _____________________________ - _____________________________

Expiration Date: _____ / _____  
Postal Code: _____________________________

Name on Card _____________________________  
Signature _____________________________

Please make my tax-free donation in HONOR / MEMORY of _____________________________

☐ Please notify them at the following address:

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**PLEASE SELECT YOUR COMPLIMENTARY SATURDAY LUNCH MEAL CHOICE(S)**

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<tr>
<td>Albacore Tuna Salad on Baguette with fresh whole fruit, pasta salad and cookie</td>
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<tr>
<td>Black Forest Ham, Brie, and Turkey on Ciabatta Bread</td>
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<td>Chicken Caesar salad with Fresh fruit salad, multi-grain roll, and a cookie</td>
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<tr>
<td>Mixed Garden Greens with Fresh fruit salad, multi-grain roll, and a cookie</td>
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**Total Selected**
and caregivers will be helpful. So, while death is inevitable in all people, a diagnosis of serious chronic illness will be different at different ages. The above examples are by no means comprehensive. There are many other variables.

Then, of course, we have to examine personality types. Some patients say, “Why me?”, while others say, “Why not me?” After the diagnosis and denial stage, were you able to define who you were/are with the illness being just one part of you, or did you allow your illness to define who you were? Did you work to educate yourself and gain power over your condition or did you get more scared and feel increasingly powerless? How much did your life change, and how many changes did you make to adjust to the illness? Did you give up most of the hobbies or activities which used to give you joy or did you try to adjust your life to incorporate as much as possible of the pre-diagnosis you?

So, in addition to age, severity of illness, support systems and personal response (rational and cognitive) versus (irrational and emotional) reaction, what else affects the “fear of dying” or “fear of not living a fulfilling life”? When psychologists are asked to appear in court to testify, they are often asked to make educated predictions. The most common response is that they don’t have crystal balls but that the best predictor of future behavior is past behavior. This is also likely to be the key in how people deal with a serious and life threatening chronic illness diagnosis. How the person has dealt with past difficult situations will be helpful in understanding how the person deals with this one. Also, interestingly, people who have been confronted with many obstacles in life and have successfully (no matter how difficult) moved forward in a positive way, or even just survived, have more resilience than those who have not been faced with previous obstacles.

People do have a choice when faced with debilitating and frightening diseases. Fear of dying is not the same as fear of how one will die, how much pain and suffering will be involved, or the quality of the life ahead. When I first read Beck’s Denial of Death in graduate school I found it more than interesting reading. Instead of doing a report on the book my classmates and I (8 of us) thought the subject matter lent itself to a simple play. Our only prop was to be a portable closet which contained a toilet. People would enter and leave the closet as others talked, obliviously, in front of the prop. The prop became symbolic of the human condition. The professor, fortunately, was amused and appreciated our interpretation.

If people are “stuck” or find themselves using old patterns which are no longer working, they may want to start questioning the need for new coping strategies – or perhaps changing longstanding schema. Patients may want objective reality checks. If people need help, or think they may need help, counseling or therapy may be considerations. With these illnesses, pemphigus and pemphigoid, the treatments can and do cause patients to be even more emotionally labile (e.g., mood swings). No one has to make this difficult, but doable, journey alone.

The bottom line is that people can make a decision to live in fear or to live; this gives people the opportunity to concentrate on life and the quality of life. It also empowers people to take more chances and to allow themselves as many experiences as possible.

So, in the end, it becomes not only a choice of fear of dying versus fear of living. There is a lot of territory to cover in between.
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