



Merry Christmas, Happy Hanukkah, Happy Holidays and A Happy, Healthy New Year

Your APF friends, Elizabeth Petit, Yvette Strange, Alexis Lockwood, Maria Gonzalez, and Desiree Lyon wish you a blessed Christmas, Hanukkah, and Holiday Season and a Happy, Healthy Joyous New Year. We have had the joy of assisting you with your questions, sharing times of sadness and happiness, providing you with the news about your disease and so much more. We look forward to helping you have a Healthy New Year.

Future Porphyria Experts

Two young physicians were selected to participate in the APF *Protect the Future* (PTF) program to train future porphyria experts. Because our own experts are approaching retirement, we must train young doctors to fill the void that will be created. Without them, porphyria expertise will be lost. The only way we can continue to train these young doctors is with your support. We do not receive any government funding yet they, too, feel that the approaching lack of future experts is a serious problem. But together we can assure that future experts will be available to treat our children and our families. Otherwise, who will we turn to for help? Who will our doctors consult with about your cases as they do now? Who will perform porphyria research? Who will write the medical text books and medical journal articles to update primary care doctors on the disease? Without training young doctors, there will be no one. We have done a good work with the training that is undergoing, but we must have your support to continue this training. Remember the APF is YOU.

This is how our PTF training works. Outstanding young doctors are selected to participate in the PTF program. They work with some of the most famous experts in the world who train them in each of the porphyrias, providing laboratory and clinical experience. The PTF doctors, also attend porphyria national and international conferences and meetings. So your future health is in the hands of these wonderful doctors who have completed training or are in training now: *Drs. Manisha Balwani, Bruce Wang, Brendan McGuire, Jennifer Guy, Jeffery Wickliff, Charles Lourenço, Angelica de Lima, Jennifer Lai, Lawrence Liu, Ryan Caballes, Tarun Narang, Manisha Thaper, Gagan Sood, Sahil Mittal, Amanpal Singh, Ashwani Singal, Maged Rizk, Sherif Abdal-Rahman, Bradley Freilich, Sajid Jalil, Chul Lee, Charles Parker, John Phillips, Guilherme Perini.*

Funding for their training also must come from our members—YOU. The annual cost of this PTF training program is approximately \$300,000. Fortunately, we will receive a \$100,000 matching grant as long as our members contribute the \$100,000 to match that grant. Their training would be a great Christmas or Holiday gift.



Dr. Maria Angelica de Faria Domingues de Lima, who hails from Rio de Janeiro, Brazil is our newest *Protect the Future* (PTF) doctor. Dr. de Lima graduated from Medical School in 2004 at Universidade Federal do Estado do Rio de Janeiro. She then began her medical residency program in Medical Genetics at Instituto Fernandes Figueira followed by her studies for a Master's Degree at Instituto Fernandes Figueira in the field of genetics and public health. She finished her Residency in Medical Genetics at the Instituto Fernandes Figueira – Fundação Oswaldo Cruz, Rio de Janeiro and her Fellowship in Oncogenetics at the Instituto Nacional do Câncer and genetics at the Latin American School of Human Genetis, Caxias do Sul. Her fourth year of medical residency was completed at Instituto Nacional do Câncer where she specialized in oncogenetics. During the last few years, Dr. de Lima has served as a genetisist at the Instituto Nacional do Câncer and a neurologist at the Hospital Universitário Gaffrée e Guinle, both of

which are in Rio de Janeiro. Dr. de Lima also works at the neurology out-patient clinic and at the Instituto Nacional do Câncer, which is a hospital specializing in cancer with an oncogenetics out-patient clinic. Ever the busy doctor, she also practices at the Hospital Universitário Gaffrée e Guinle in the genetics out-patient clinic. There she follows many genetic diseases and now she has added porphyria. (Continued on page 2, See **Dr. de Lima.**)

Dr. de Lima *(Continued from page 1.)*

As part of our *Protect the Future* program to train future porphyria experts, Dr. de Lima recently had the opportunity to train with Dr. Robert Desnick at the Department of Human Genetics at Mount Sinai School of Medicine in New York City and with Dr. Karl Anderson at the University of Texas Medical Branch in Galveston. She joined other PTF colleagues for Porphyria Training Week, October 17-21, at the Porphyria Center at the UTMB. Dr. de Lima is single and lives with her two dogs: Bono, a chocolate Labrador Retriever and "The Edge," a Golden Retriever. According to Dr. De Lima, Bono and "The Edge" are two and a half years old and think they are her kids!! When she is not working or caring for her two "kids," she loves to watch movies, study photography and take photographs, read and travel. Dr. de Lima joins our two other Brazilian PTF doctors, Dr. Guilherme Perini and Dr. Charles Lourenço. We welcome her to our porphyria team.



Amanpal Singh, MD, MS is one of our newest *Protect the Future* (PTF) doctors training with porphyria specialist, Dr. Karl Anderson. Dr. Singh is a Gastroenterology and Liver expert at University of Texas Medical Branch, Galveston, Texas where he serves as the Chief Fellow, in the Department of Gastroenterology. After finishing medical school at the most prestigious institution in India, All India Institute of Medical Sciences, he received a Master's degree in Epidemiology from Harvard University.

Currently, Dr. Singh is collaborating with Dr. Karl Anderson to study the epidemiology of porphyrias and patterns of care for porphyria patients in the United States using claims based database. He brings his wide experience working with large databases, like the national Medicare claims database, to help determine baseline data on the burden of disease and quality of care that porphyria patients receive. Dr. Singh is also managing porphyria patients with Dr. Anderson. Porphyria patients travel to the Texas Porphyria Center from around the nation and even internationally to seek expert care for their particular type of porphyria. They come for diagnosis and treatment, thus, giving Dr. Singh clinical experience in all types of porphyria. In either case, most of the patients have endured a host of tests without receiving a diagnosis and are very grateful when they receive a diagnosis at UTMB. Aside from his main medical interests, Dr. Singh is involved in performing comparative effectiveness research and health services research and has accumulated an extensive list of peer reviewed publications and presentations Dr. Singh recently attended the PTF Training Week with other PTF doctors at the UTMB Porphyria Center. We are grateful that he will be counted among the future experts. We are proud to have a physician of Dr. Singh's caliber. WELCOME !!!!!!!

Lundbeck Visit



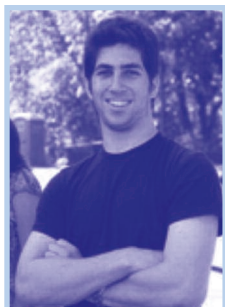
Because many of our APF members receive Panhematin as a life-saving and/or preventive measure, we invited Paul Sticker to visit our office. Paul is the Vice President and General Manager of Hospital and Hematology for Lundbeck, Inc., the company that manufactures Panhematin, which is the only drug for the acute porphyrias. Our mission was to ask if Lundbeck had educational materials on AIP that we might study as we expand our physician education campaign. We also wanted to share patient stories about how Panhematin had saved their lives, shortened attacks, prevented attacks, etc. Unfortunately, many people who contacted us were not able to receive Panhematin even though they needed it. We are trying to understand those reasons more fully to better help YOU our members. If you have been denied treatment for an acute porphyria, please contact Desiree at the APF.

FirstGiving is a easy, effective, and even fun way for you to raise money online. You can create your own fundraising activities using the internet with simple, yet powerful tools. You can create your own fundraising goals and track your own efforts. For example, Rob Saupe is walking 100 miles in 45 days to support the APF physician education program. He sends a link to his FirstGiving site to his email list where his friends can easily make a donation to support his WALK. Desiree will be sending her link to her email list, too, asking her friends to also support the APF *Protect the Future* program. We need you to join us. It is an easy way to help physicians understand and better treat porphyria. See: <http://www.firstgiving.com/americanporphyriafoundation>.

Medicare Changes

Porphyria specialist, Dr. Herbert Bonkovsky, represented porphyria patients, recently when he met with the Centers for Medicare and Medicaid Services' (CMS's) to address the proposed rule titled "Medicare Program; Proposed Changes to the Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals and the Long-Term Care Hospital Prospective Payment System and Fiscal Year 2012 Rates." In short, this is about how Medicare denotes and pays (MS-DRG) for certain diseases, so it was appropriate that Dr. Bonkovsky be the expert explaining acute porphyria and its treatment, as he was the first physician to administer heme therapy (now Panhematin). Desiree Lyon Howe, executive Director of the APF participated in a conference call with the CMS attendees.

The purpose of the meeting was to recommend that CMS create a new MS-DRG specifically for cases with a primary diagnosis of porphyria to ensure appropriate payment for these more costly cases and to preserve patient access to necessary treatments. After distributing and receiving several surveys to our members, we discovered that many of our members who were on Medicare were not receiving the treatments they needed. Please contact the APF if you are on Medicare and were denied access to treatment, namely Panhematin. Ask to speak to Desiree. We sincerely thank Dr. Bonkovsky for helping patients gain better access to treatment.



Patient's Perspectives: Andrew Turrell

Although I was not diagnosed with porphyria until I was 10 years old, I have always suffered from the pain caused by spending too much time in the sun. As far back as I can remember beach vacations and summer camp were always linked with itching, burning and sleepless nights. Before I was able to verbally articulate the sensation, the only reason my parents believed that the pain was real was because I would continue to scratch my hands and face even once asleep (fortunately, I do not get blisters or other visible symptoms). I visited a number of doctors and was tested for a variety of allergies, but nothing stopped the reactions. Every summer, I would inevitably experience a handful of painful reactions that would last between two and three days. Ice packs and cool wet towels were the only things that could alleviate the itching and burning. Unable to sleep, I would hole up in the basement because that was the coolest place in the house.

By chance my parents after one of my reactions, were talking to an acquaintance who is a dermatologist. She diagnosed me on the spot without ever having seen me and suggested that I go to see Dr. Vincent Deleo. I did so, and he diagnosed me, put me on Lumitene and recommended certain sunscreens. Over time, I learned to take better care of myself and prevent reactions by reapplying copious amounts of sunscreen, wearing pants and long sleeves and avoiding sun exposure whenever possible. Even with all those precautions, I still continued to suffer a few reactions each year.

Since I was a young kid, I have always loved baseball. Despite my EPP, I have continued playing and have recently started coaching as well. I wear long sleeved turtlenecks even on the hottest days of summer, and while playing baseball has caused the vast majority of my reactions, it has been worth it.

Last year, I participated in the *Afamelanotide* trials at Mount Sinai Hospital in New York. That summer, I spent more time outside than ever before and yet I did experience one bad reaction. Currently, I am a student at the University of Pennsylvania where I am active in my fraternity, Psi Upsilon, and play on the club baseball team, eagerly awaiting the approval of *Afamelanotide* by the FDA. *Andrew is the administrator of the new FACEBOOK group for young adults called, 26° Below !*

Read the rest of the following stories in the Members Section of the APF website.

APF FACEBOOK GROUPS.....

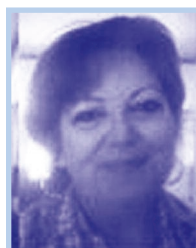


Our newest APF FACEBOOK group is **EPP PORPHYRIA 26°**, which was created only for young adults with EPP, thus the name 26° Below. To become a member of the group, you need a FACEBOOK account and go to www.facebook.com/groups/190013374399363/?ref=ts. Join Andrew Turrell, who is the administrator, and a number of other members from around the world. Addition to the main APF group that is open to all, there also are separate groups for each type of porphyria; EPP & CEP, PCT, AIP, VP & HCP which are closed groups to better protect the members privacy. You can join these groups on FACEBOOK:

http://www.facebook.com/pages/AmericanPorphyriaFoundation/269339899743266?sk=app_221460014534454est

Vickie Coley Gehm

I was almost 16 when my mother passed away from porphyria in 1982. She was technically diagnosed with PCT. At one point, my mother was on the court of our town's 100th year celebration and she looked absolutely beautiful. This was before I was born, and she seemed extremely happy and radiant! From what I remember, my mother always had something wrong, but local doctors were diagnosing her incorrectly and really weren't sure what was going on with her. Finally, someone sent her to Mayo Clinic and they gave a name to her symptoms, Porphyria Cutanea Tarda.



Kathryn Nelson

My Porphyria Cutanea Tarda (PCT) experience began roughly seven years ago. At the time, I was living in Irving, Texas. When lesions appeared on my face, forearms and legs, I thought that perhaps it was related to Psoriasis, an autoimmune disorder I had since I was a child. As a result, I resorted to a fairly common approach to Psoriasis which is exposure to UV rays. I spent an hour or so every afternoon in the sun, but more lesions developed and the existing ones grew in size. Repeated visits to my dermatologist resulted in a variety of misdiagnoses. I continued to use antibiotic ointments on the most severe patches and, as a result of other health concerns, discontinued my efforts to get a daily dose of UV rays.

Over time, the lesions began to shrink but a new symptom developed. My skin darkened dramatically in areas where there were no blisters and where the blisters had healed, the skin turned white, giving the appearance of vitiligo. I was seeing a Rheumatologist for other autoimmune symptoms and he suggested I visit a dermatologist he knew who specialized in autoimmune skin disorders. Things changed for the better when I met Dr. Melissa Costner in Dallas.

Angela Rossi

My name is Angela Rossi and I was diagnosed with AIP in 2003 and have been receiving Panhematin once a month for four days straight and have not had a severe attack since getting the Panhematin. I do get mild attacks every so often but not the bad ones that I had previous to the Panhematin.

I went through so much testing before becoming diagnosed with porphyria, including CT Scans, MRI'S, barium studies and hundreds of blood tests. What I remember most was enduring an extremely painful Bone Marrow Biopsy. *Angela said she would like to hear from you via the APF.*



Clara Hauke

I am 18 years old and am from Germany. I have pain after staying in the sun since I'm about 2 years old. All of a sudden, I started crying but nobody knew why. My parents even wondered if I was pretending or not. Slowly

they figured it had to do with the sun. We tried so many things and we went from doctor to doctor, but nobody had a clue what exactly my problem was. Several times my eyes were so swollen I couldn't see anything. In summer, it was horrible. At night I couldn't sleep, I itched myself till I was bloody – awake or sleeping. The only solution for me was to protect myself and stay out of the sun. But I just didn't want to be different from my friends, and I didn't want to be a burden for my family.

So I often crossed the "sun border," to make it possible for my family to take me with them. When I was about six or seven, I met a doctor who guessed what my problem was. She sent me to a university hospital, where my family and I got a diagnosis: Erythropoietic Protoporphyrin (EPP). Just this fact helped us a lot.

Mike Gaudino

I'm 17 years old and I am currently a senior in High School. I was diagnosed with EPP when I was either three or four. My parents said they would take me to the beach when I was little, and all I would do was cry and scream. So I got tested and had EPP. It really sucks because you can't do more than half the things a normal teenager would be doing. I can't swim for long, I usually go in ten minute intervals. When I get a reaction it feels like someone is sticking my hands in the oven, and freezing them at the same time. The reaction for me takes about a week to get back to 100%. The pain doesn't go away in that week either, it just kinda stays with me all of the time. I do golf and play baseball though with long sleeves, long pants, hat, gloves. It's hard to golf because I've had to leave about five school golf matches on the fourth hole which is no fun, and embarrassing. It limits a lot of activities, but I'd rather me have EPP than someone else, because I'd never want anyone to go through what it feels like. I hate going to the beach because I sit inside all day, but I really take advantage of the winter, and go skiing.

EPP Trials Show GOOD NEWS

Analysis of the data of the recent EPP trials show GOOD NEWS.

Clinuvel demonstrates positive treatment effect of afamelanotide in U.S. Phase II study: <http://www.clinuvel.com/resources/cmsfiles/pdf/20111103USPHIIIPP.pdf>



Victor Mejias, who was a patient volunteer in the trials also shares GOOD NEWS. He and his bride, Sue Birmingham, celebrated their wedding Nov. 5.

Congratulations!

EPP Poetry



Poem about EPP©

Patricia Parsons-Beetschen

Normal...Who put the tag on that?

Certainly not me,

I have what is called, "EPP".

Initials, you say, What does it mean?

Is it a texting shortcut?

Or something unseen?

Erythropoietic Protoporphyrin, A poem? A disease?

Or a new type of Wisteria?

It means EPP. A rare genetic enzyme flaw

Totally misunderstood by all

Except for a selected few And, even they don't know

what to do. Affected by sunlight By daily admission,

is delineated by This painful condition.

Laughter befalls the quickness of jest

Providing a proclamation of a "Vampire" at best.

Preferring the shadows than the light of day

Directing their lives in a deliberate way.

Misunderstood is hardly quite right

When daily a battle begins at dawn's light.

Normal? My normal is living with EPP.

Educate yourself about it...Then you might understand

that part of me.

EPP © by Georgina Davies

Look at the lucky people having fun.

They can go out in the sun,

Scantily clad in the heat of the day.

If we did that, oh how we'd pay,

But, we are rare, not many like us.

Who, when the sun comes out,

We 'make a fuss'. We have a genetic condition you see,

And it goes by the name of

Erythropoietic Protoporphyrin aka EPP.

Isolation is its game. While others play and have fun,

We hide indoors away from the sun.

If we dare try to fit in,

My oh my, watch out for the pain to begin.

The slightest exposure can cause such pain,

That we don't want to go out again.

Feeling as though our bloods on the boil,

And lack of understanding for all our toil.

Swelling and itching all part of the course,

When into the sun we are forced.

With large floppy hats, long sleeves and gloves,

Covered right up from our heads to our toes.

What a funny sight to see,

People, like us, who suffer from EPP.

Dr. John Phillips



In case you can't see what is in Dr. John Phillips' hand, it is a First Place ribbon for his delicious Honey. When he is not performing important porphyria research, he is enjoying his hobby as a Beekeeper!!! Fortunately for all of us, Dr. Phillips is a brilliant researcher in the Hematology Department at the University of Utah at Salt Lake City, Utah. Many of our members know Dr. Phillips, especially those of

you who participated in the *Afamelanotide* clinical trials. In the laboratory, he and his colleagues study the synthesis of heme. In humans, defects in any of the eight steps involved in heme synthesis are termed the porphyrias. The most common of the porphyrias is Porphyria Cutanea Tarda (PCT) that is due to reduced activity of (URO-D).

His laboratory has primarily focused on this fifth step using a combination of biochemistry, mouse genetics and structural studies to understand the molecular basis of the disease. Since there are both environmental and genetic components to the development of PCT, they have constructed a mouse model of the familial form of PCT and have also developed an environmental model of PCT using environmental toxins such as polychlorinated biphenyls (PCB's). In all cases, the phenotype of PCT (blisters on sun exposed areas of skin, excess porphyrins in urine and excess iron) is due to an inhibitor of the enzyme. Using these mouse models of PCT, they are identifying the changes that occur in the liver that lead to the production of an inhibitor of URO-D. But how does he also produce Blue Ribbon honey???



Canadian Support



For over twenty years, Canadians have received information, knowledge, understanding, and assistance from the Canadian Association for Porphyria. In 2010, the Canadian Association for Porphyria ceased to exist due to lack of support. In order to continue their work, a small group of supportive people have been meeting in Edmonton, Alberta to start a local, not-for-profit organization. They are following, slowly but surely, in the footsteps of Lois Aitken, former organizer and president of the Canadian Association for Porphyria. *The Alberta Porphyria Society (APS)* formally emerged at their initial meeting on Saturday, October 15th, 2011 in Edmonton, Alberta, Canada. The interim board and members brainstormed about ways to fulfill the organization's goals and set the agenda for a general meeting in the New Year. Of course, stories about living with porphyria were shared by those around the table. Members of the APS look forward to providing support and information to those with questions concerning this little-known disease. If you would like more information, contact: albertaporphyria@gmail.com.

National Porphyria Registry

Porphyria experts have created a National Porphyria Registry—a type of partnership between doctors and patients—a way for those with porphyria to share information about their health and treatment so physicians can learn from their experience and use that knowledge to enhance care. Because porphyria is rare, it can be hard for doctors to make fast and firm predictions about how the disease will act in a given patient, or how a treatment will affect an individual. A patient registry can help doctors learn more about the porphyrias and helps them to help patients. The contact registry is a way for patients to be contacted about clinical research opportunities and progress. It is anonymous and free of charge. All data will be stored in a secure, computerized database. No personal identifying information (such as your name, address, telephone number) will be given to anyone without your expressed approval. People who join the Registry will be contacted by one of the porphyria experts who are members of the Porphyria Clinical Research Consortium.

The registry is not linked to APF membership, but we hope you will join the American Porphyria Foundation too! Our diseases are rare, so we need to speak up and represent our own concerns. The APF has played an active and ongoing part in establishing and supporting the porphyria Consortium, and supports porphyria patients and families through education, awareness and advocacy in hospitals, funding agencies and the media.

Join the Registry by clicking on the Porphyria Registry tab on the home page of the APF website.



NHGRI The National Human Genome Research Institute created the Talking Glossary of Genetic Terms to help everyone understand the terms and concepts used in genetic research. In addition to definitions, specialists in the field of genetics share their descriptions of terms, and many terms include images, animation and links to related terms. For this educational experience, go to www.genome.gov where you will find many more interesting programs.

APF 30th Anniversary

Good News!!! Next year is our 30th Anniversary. We will have lots of events to celebrate: Patient Meetings, Night-time Fun Runs, and Conference Calls with Experts and an opportunity for you to plan your own FUNdraising events on the internet with *First Giving*.

Take a look at what Rob Saupe is doing
<http://www.tinyurl.com/3crd831>



Porphyria Live DVD

Order one and get one free for your doctor. If you have not seen the APF DVD *PORPHYRIA LIVE*, you will enjoy it immensely and be privy to an outstanding educational tool. Order *PORPHYRIA LIVE* today and receive one free for your doctor or another family member. The DVD includes a number of exceptional interviews, including porphyria experts, Dr. Robert Desnick, and Dr. Karl Anderson, who make outstanding presentations on each of the porphyrias, explaining the differences in the types of porphyria and their ongoing research. The doctors also take the viewer through their research laboratories and hospitals, namely Mount Sinai Medical School (Desnick) and

The University of Texas Medical Branch (Anderson). You can watch as laboratory technicians are hard at work running porphyria tests and performing important research for improved diagnosis and treatment. Dr. Sylvia Bottomley, who was involved in much of this life saving research and who continues to write porphyria chapters in medical text books, expands on the explanation and history of the diseases. During her interview, she answers the questions we hear most often at the APF about diagnosis and treatment.

Patients with each type of porphyria are also interviewed at their homes and at the hospitals. Among them are Ann Warnke and Karen Eubanks. Ann, who has EPP, is seen in her garden, well covered to protect her from the sun. Karen is filmed in her hospital bed receiving an infusion of Panhematin to stop her attack of AIP. Since being a "caretaker" for porphyria patients is very challenging and often difficult, we interview the spouse of several patients and found these to be some of the most poignant moments. The DVD answers most of the questions we hear when patients contact the APF. You and your doctor or additional family members will know the FACTS about the different types of porphyria and will gain a greater understanding of the illness by watching this outstanding DVD, *Porphyria Live*. Order the DVD for \$20 and get one for your doctor or family members free. Remember to give us the additional address. Call 1 866.APF.3635 or email: porphyrus@aol.com.



Bargain Price, Last on the Shelf

You can also purchase Desiree's book for yourself and family members and get a DVD free for only \$20. *Porphyria, A Lion's Share of Trouble* shares a history of the APF and great descriptions of each porphyria, as well as a lengthy selection of personal experiences from patients who suffer from each of the different porphyrias. Their stories on every type of porphyria are educational, sad, heart wrenching, and often even humorous. Aside from the acute porphyrias, Desiree also discusses the difficulties that people with EPP and PCT face. All proceeds go to the APF.

Research

Dr. Ryan Caballes, who is one of the APF/PTF doctors, at the Carolinas Medical Center joins Dr. Herbert Bonkovsky as one of the researchers in a pilot study to investigate the circadian rhythms of patients with acute intermittent porphyria. The study will attempt to determine whether circadian rhythms are altered in subjects with biochemically active AIP, which may possibly explain why such patients complain of mood or sleep disturbances. Subjects are monitored by a member of the research team throughout the 24 hour period to address any of their concerns and assure their safety and comfort.

They need to recruit eligible patients to participate in this study. After the day of the study, volunteers may either return home or choose to stay in Charlotte for some rest and relaxation at their own expense. In addition to free travel, food, and lodging overnight, patients will receive a \$300.00 honorarium as a sign of appreciation for their time and effort. Please contact the APF if you want to participate in this study or study coordinator, Gale Groseclose at gale.groseclose@carolinashealthcre.org

With Love

We are grateful when members choose to honor a friend or family member with a gift to the APF. It shows the donors love and also their trust that the APF will fulfill the mission of bettering the world of patients.

In Memory

We are saddened to hear of the passing of dear friends. Some of their loved ones have chosen to honor a life by making a gift to the APF. We sincerely appreciate their thoughtfulness. Please join us in thanking: Patricia and Roy Julius, Winona and Junior Pruitt, Beatrice and Robert Darmon, Brenda and Robert Ferguson, Carolyn S. May, Dorothy Logan, Kitty Carriker and Gerry McCartney, Miriam and Donovan Moore, Diane Z. Park for *Bill Carriker*; Kathleen Toelkes for *Donna Pagano*; Kitty Carriker and Gerry McCarney for *Willard M. Carriker*; Dale Brehm for *Geroge Brehm*; Greg Williams and Jeff Jonas, Donna and Darnell Pettengill, Rebecca and Michael Williams, Robert Arnold, Jim Rowles, Perry Cartlidge, Bridget Walker, Jo Still, Diane Hesselbein, Mack Stallings, Mamie Douglas, Greg Tims, Henry Hamill for *Deborah L. Williams*; Margaret and Charles Renner for *Jody Bela* and *Glenn Gentry*. Marie and Frank Jackson for *Nancy Ford Drury*.

In Honor

We are sincerely appreciate your honoring these beloved friend and family members: Sharon I. Koch for *Jagger and Jake Liguori*; Carol Fontani for *Mira Geffner*; Eric S. Gray for *Ralph Gray*.

Porphyria Training Week



October 17-21, 2011 was **Protect the Future Porphyria Training Week** at the Porphyria Center at the University of Texas Medical Branch in Galveston, Texas. Attending were young doctors who were selected to participate in the PTF program to train future experts. Dr. Karl Anderson, who is Director of the Porphyria Center, set up a week of training so that the young doctors could have experience in the laboratory to understand the unique testing for porphyria and participate in the research transpiring at UTMB. Dr. Anderson also scheduled patients with every type of porphyria so that the doctors could meet the patients and hear their personal experiences with the disease.

Several of the young doctors mentioned that they had never met patients with certain extremely rare porphyrias, like CEP. They also appreciated the opportunity to have such in depth training. Without porphyria experts, like Dr. Anderson, volunteering to train these young doctors, their expertise would be lost. Like other porphyria experts who are concerned that the present level of expertise will be lost as the present experts retire, Dr. Anderson has devoted his time to the PTF program and has trained many of the PTF doctors. This Training Week will be an annual event at the UTMB Porphyria Center. The process to select more young doctors is underway. Dr. Anderson deserves our thanks for his dedication to porphyria patients and his extraordinary participation in the PTF training program to assure them that porphyria expertise will not be lost as our present group of experts approach retirement.

The participants as shown in the photo were left to right front: *Desiree Lyon Howe* and *Dr. Karl Anderson*. Back row: *Drs. Guilherme Perini, Maged Rizk, Sahil Mittal, and Angelica de Lima*. *Dr. Amanpal Singh* was not present.

EPP Documentary

APF member, Monica Fleegel and her family were the subjects of a recent documentary on how EPP affects families. Hans Huebner, who is a producer with the RTL Television and Radio Network, contacted the APF as he had done in years past. This time, he wanted to take a different slant. Instead of focusing his documentary on one family member with EPP, Hans wanted to focus on family members who do and do not have EPP and how they deal with the disease. We had just the right family for them. We contacted Monica Fleegel who is from a family in which five out of nine children have EPP. The family agreed to work with Hans and spent two days collaborating on a documentary revealing how people with EPP avoid the sun, how families help them and how it is difficult on families who don't have the disease, too. Monica said it was good for the family "to be able to talk about EPP and what it has meant to us as kids and adults."



The RTL network is the number one TV and Radio Broadcasting network in Europe. Since RTL has 41 TV channels and 34 radio stations in 10 countries airing this documentary will greatly enhance EPP awareness. In the documentary, viewers will see how the family with EPP protects themselves. Since the sun is the culprit, they dress in sun protective clothing, play golf at night, and live a life that is mindful of every ray of sun. We are grateful to Monica Fleegel, Tom Foley, Rita Kitzberger, Theresa Westrup and their families for participating in this wonderful opportunity to enhance EPP awareness and allow people to understand what life is like to be severely photosensitive. We also thank the RTL network, Hans and Brian, the cameraman. **THINK EPP.**

Lyons Share



I first want to update you on the Bill HR2674 related to the 340 B hospital drug pricing. **WE ARE GAINING GROUND.** Congressmen have told us that they have heard from YOU. Please keep up the good work—don't stop! As your representative, I traveled to D.C. to tell Congressman for two days straight that if they did not put an exclusion in this bill for rare disease, many rare disease drugs will no longer be produced and people will DIE.

For those who do not know of this issue, in short, thousands of hospitals will be able to buy drugs for less than it cost to manufacture the drugs. No company can continue to make a product for more than they can sell it!!!! Panhematin, for example, is a biologic and is very costly to manufacture. Many, many people are alive today because of Panhematin, including me and so many of my APF friends. They need Panhematin to stay alive or lessen the suffering of an attack. Yes, HR 2674 will lower the price of drugs to these hospitals. For blockbuster drugs, this is good for patients, but for rare disease patients, this is a catastrophe!!! Please call your Congressman on this life and death issue. Call the APF office if you need more info.



The information contained on the American Porphyria Foundation (APF) Web site or in the APF newsletter is provided for your general information only.

The APF does not give medical advice or engage in the practice of medicine. The APF under no circumstances recommends particular treatments for specific individuals, and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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What's New at the APF www.porphyrifoundation.com

Doctors are Recruiting Patients Now for clinical research studies. A \$4.4 million grant from NIH has jump-started clinical studies for PCT, EPP and acute porphyrias. Please call our office for details to be contacted by researchers.

Holiday Gift Giving: Remember the APF in your holiday shopping this year. Visit Amazon or other vendors via the APF website, or honor a loved one with a donation. See page 1, or call our office for details.

Tell your doctor about the **Safe/Unsafe Drug Database for Acute Porphyria** and **Emergency Room Guidelines for Acute Porphyrias**. All medical information we distribute is written by porphyria specialists.

Is Your Membership Up to Date? Don't miss a newsletter! Please take a moment to renew at our website, or call us at the office: 713-266-9617 or 866-APF-3635. *Thank You.*

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