New PTF Doctor: Siddesh Besur, MD, FACP The APF welcomes our newest *Protect the Future* (PTF) trainee, Dr. Siddesh Besur. Dr. Besur will be training with porphyria expert, Dr. Herbert Bonkovsky at the Carolinas HealthCare Systems in Charlotte, NC. Dr. Besur completed the Transplant Hepatology Fellowship in Carolinas Medical Center/University of North Carolina in 2013-2014. He was a Clinical Fellow Internal Medicine at Royal Glamorgan Hospital in the United Kingdom during 2003-2004 and a Fellow in Internal Medicine at the University Hospital of Wales in the United Kingdom during 2000-2003. A few of his Awards and Honors include:

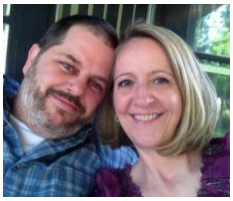
- Master in patient teaching physician-outstanding teacher award - 2012, 2013
- Faculty Investigator Award Michigan State University-FAME - 2013
- Elected fellow of American College of Physicians (ACP) - 2011
- American Society of Transplantation travel grant - 2013
- Presidential Poster award - American College of Gastroenterology - 2012
- First prize - Research presentations at Southern Hospital Medicine - 2011
- First prize - Health policy and medical education presentations at Michigan State Medical Society - 2011

We are glad to have Dr. Besur as one of our PTF trainees. The PTF program was initiated to train young doctors as the next generation of porphyria experts. Each trainee studies with one of the porphyria experts for a lengthy period of time, as well as attends national and international porphyria medical meetings. Your donations support this important program. Please consider your participation with the donations marked as "For PTF." *Thank you!*

Pierre Mouledoux Changes Louisiana Law For EPP <u>Pierre's story shows what one person can do. You, too, can help change the law for the benefit of patients in your state</u>.

Phew! What a long battle for a yearly brake tag! Most would think enduring Erythropoietic Protoporphyria (EPP) would be challenging enough. No. Not quite. Insert politicians and the "public safety" train of thought and poof: new laws, new requirements, and new headaches all for a $10 Brake Tag! Every year in Louisiana a brake tag (everywhere else known as a vehicle inspection sticker) is mandatory. In March 2013, when it was time for my truck (with its blacked out tinted windows) to be inspected, I noticed that my medical exemption had expired in January. It was a simple process: your doctor signs a form certifying your disease with your vehicle information signed by you, notarized and then sent in for approval by the Louisiana State Police. I had become accustomed to the multi-step process, but unaware of a change in the law, my tinted windshield was now illegal. The past law allowed for full tinting of your car's windows and windshield with an approved medical exemption. After some politicians' concern for "public safety" in 2008, I now have to be fingerprinted, subjected to background checks, and yet another inspection by a Louisiana State Trooper who's going to give you another additional inspection sticker stating you have a medical condition. I contacted my local representative, Cameron Henry, in mid-March to find out what was taking so long. Rep. Henry's staff hustled the process along and a few weeks later, a Louisiana State Trooper contacted me to schedule the inspection of my vehicle and to install the additional sticker which would allow me to get a mandated brake tag. By this point, my brake tag had been expired and with each passing police officer, I wondered if my excuse of "My medical exemption is pending" would suffice. The trooper informed me that the full windshield tint was not grandfathered in and was now non-permissible with a medical exemption. He told me that no administrative fix or additional exemption would be granted and that the resolution was to remove my tint. I declined removing my tint and was left with two choices: change the law or file a lawsuit.

2013 was a busy year for me with many firsts: buying a home, having our first child and now having to change a law. Moving put me outside the district of the representative who initially spearheaded this legislative change for me and other Porphyria sufferers in Louisiana. Without skipping a beat, I contacted my new representative, Joe Lopinto who filed House Bill 1127 for our cause. I learned that the law had to be very specific, so Rep. Lopinto and I narrowed the scope of the original bill to "for a patient who is diagnosed with a light-sensitive Porphyria", which satisfied the State Police's and the legislators' concerns. After the addition of the specific condition, HB1127 passed committee 12-0. The bill also passed the full House and the Louisiana Senate. On June 5, 2014, Louisiana Governor Bobby Jindal signed House Bill 1127 into law, and it now stands forever in time as ACT 433. The addition of the new laws for the requirements of fingerprinting and background checks has significantly reduced the abuse of the medical exemption. For those states that do not have any provisions for medical exemptions for window tinting for Porphyria patients and that refuse to enact any laws due to fear of abuse,, follow the Louisiana model. The more narrow/specific a law becomes, the more accepting it is for those who are "public safety" minded. See www.legis.la.gov, and research the Louisiana Revised Statutes 32:361.1, 32:361.2 and Act 433 (effective August 1). After everything I went through, a year and a half later, I can finally get a brake tag on August 1st when the law becomes effective. I've waited this long; two months is nothing! Thank you, Pierre, for your amazing effort.



Victor and EPP

I push myself to go to work all week....
I push myself to do work around the house....
I push myself to be with family and friends....
I push myself to do the things I love to do....
I'm on Fire, can't sleep and depressed. EPP problems!

APF members enjoy hearing your experiences. Please Share Your Story!

Victor Mejias is a graphic artist and a lifelong resident of the Chicago area. Victor was diagnosed with EPP at age six. Now, he serves as one of the APF Facebook Administrators for EPP and is replete with good suggestions to improve communication. He is well known in the EPP community and is greatly admired not only for helping so many with EPP, but also for sharing his wonderful sense of humor with us all. Many times when things are tough, Victor gives the group a good laugh!!! As you know, laughter is healing to the soul. Victor has three kids: Britany, Riley and Dusty. He loves to fish and does whatever it takes to get in a good day of fishing: "Fishing is my passion and if I could I'd do it full time." Victor also was a participant in the Phase II clinical trials with Afamelanotide, the new EPP treatment. Victor has assisted us in our communications with the FDA and even provided some of the most powerful quotes to use to describe EPP to the FDA and their European counterpart, the EMA. We are proud to have Victor and his bride, Sue, as APF members.

Amanda Boston Medical Hero: Panhematin® Research Today we are sharing Amanda Boston's experience with you. Amanda has Variegate Porphyria (VP) and is currently enrolled in one of the important clinical trials with Dr. Anderson at the University of Texas Medical Branch, Galveston TX:

"*I had the most amazing privilege participating in the "7203: A double-blind, randomized, placebo-controlled, parallel group trial on the efficacy and safety of Panhematin® in the treatment of acute attacks of porphyria" research study. I met two amazing doctors that I had only spoken with through email and telephone: Dr. Karl Anderson and Dr. Akshata Moghe.*

The research was performed in Galveston, TX at UTMB. I was flown into Houston and transported to Galveston. I stayed at the Harbor Hotel until I developed symptoms of an attack, which occurred two days after my arrival, as my attacks are very frequent. For the research, I was blindfolded, the drapes were drawn and foil wrap was put on the cords, so that I wouldn't know if I were getting a placebo or Panhematin®, but my body knows the difference. I was started on the research, but my headaches and abdominal pain were only getting worse. I was about to start an attack. Panhematin® was brought in and administered to me, and I began feeling better the next day. Panhematin® is, indeed a truly effective treatment for acute porphyria.

My whole reason for doing this research was to help others and to show that Panhematin® does work. When I first got to UTMB for the research, I found out that I was the first research patient on this particular study. That is a wonderful privilege. I feel a great sense of accomplishment by participating in the Panhematin® research study. I feel that I really accomplished my goal, because I was given the opportunity to help others. I thank the APF for helping me to make my goal a reality. Dr. Anderson is the one who developed and oversaw the research. He is an amazing doctor and porphyria expert. He knew exactly what I needed from the moment I walked into the research clinic. I've never met a doctor that was so educated on porphyria and so devoted to the research and helping one's suffering from porphyria. Also, he is the nicest person you will ever meet. If anyone with Porphyria has the chance and is thinking about being on a research study, I would suggest that you take that opportunity. It is the greatest privilege you will ever have." Thank you for participating and sharing your inspiring story with all of us, Amanda!

Letters to your doctors are being sent describing this research project. If you have recurrent attacks and would like to participate in this study, please contact the APF. If your doctor is not on the APF list, please contact us with his/her name and address and your doctor will receive all these updates.

Members, the Porphyria Research Consortium needs YOUR help! Also remember, that there are other research projects you can join. Please consider being a part of important ongoing clinical trials for each type of porphyria, plus there are family studies for family members. Contact the APF office at 713.266.9617 if you would like to be a volunteer for the research projects for AIP, HCP, VP, EPP, PCT, CEP. **Be a Medical Hero.**

Support the APF with AmazonSmile for Charitable Organizations! Now you can support the APF through the AmazonSmile program! Amazon will donate 0.5-0.8% of the price of your eligible purchases to us, at no cost to you. Please make us your choice of a charitable organization, support the research while shopping!

Please note, the program will only be available to shoppers who visit Amazon via a special web address — smile.amazon.com — instead of the normal Amazon.com homepage.

It is easy and free, AmazonSmile is the same Amazon you know. Same products, same prices, same service. Thank you for supporting us! Please follow the link: http://smile.amazon.com/ch/36-4401266

The Longitudinal Study and the CME Course The APF has sent out letters to all physicians from our data base about the Longitudinal Study of the Porphyrias. We also provide information about the CME (Continuing Medical Education) course (a free, internet-based activity). The title of the course reads: "The Management of Acute Porphyrias: Improving Diagnosis, Treatment, and Standards of Care."

This activity is intended for gastroenterologists, hepatologists, emergency department physicians and nurses, hematologists, oncologists, obstetricians/gynecologists, primary care providers, dermatologists, endocrinologists, nurses, pharmacists, and other healthcare professionals who manage patients with acute porphyrias.

The goal of this activity is to explore the challenges involved across specialties in identifying and managing patients with acute porphyrias.

Upon completion of this activity, participants will be able to:

1.Detail the history, signs, and symptoms that point toward an appropriate diagnosis of acute porphyria

2.Discuss the optimal methods for making the diagnosis of acute porphyria

3.Evaluate acute and long-term porphyria treatment options

Authors & Affiliations: Herbert L. Bonkovsky, MD, Owen M. Lander, MD, Gale W. Groseclose, RN, BSN.

If you would like us to send your doctor information about the current studies and a CME card, please contact the APF: 713.266.9617. Remember that the APF will send a very comprehensive doctor packet to your doctor.

A Natural History Study of Acute Hepatic Porphyria (AHP) Patients with Recurrent Attacks

With the help of the Porphyria Research Consortium, Alnylam will be conducting a study to include patients with the three most common AHPs, which include acute intermittent porphyria (AIP), variegate porphyria (VP), and hereditary coproporphyria (HCP). Consented eligible patients with a history of recurrent attacks will be enrolled for the study and return to the study sites for a visit approximately 6 months later. A detailed medical history and a medication use history (including herbal or vitamin supplements) will be collected for the period since the patient's porphyria diagnosis or onset of symptoms, but in general at least 24 months prior to the Baseline Visit. In addition to undergoing physical examinations at each site visit, patients will also have blood and urine testing (to measure delta-aminolevulinic acid (ALA) and porphobilinogen (PBG) and complete quality of life (QoL), pain, and healthcare utilization assessments. Additional blood and urine samples will be collected for biomarker exploratory analyses. Site staff will call the patient approximately every 2 months after the Baseline Visit to collect general health information, complete a porphyria phone assessment, and to remind patients to send a urine sample to the central laboratory. If a patient experiences a porphyria attack during the study period and is treated at the site, urine and plasma samples, porphyria attack questionnaires, and an attack treatment form will be collected. Site staff will also call the patient approximately 1 week and 2 weeks after treatment for the attack is completed to collect information for a porphyria assessment.

Please, contact the APF if you live near OR are willing do drive (the driving expenses will be reimbursed to you) to the following cities in the USA and countries: Birmingham, AL; San Francisco, CA; New York, NY; Charlotte, NC; Galveston, TX; Salt Lake City, UT. Internationally in the UK, France, Switzerland, Italy, Norway, Sweden, Finland, the Netherlands, Czech Republic and Poland.

Our Friends from the French Porphyria Association have a wonderful international opportunity. They are asking all EPP patients and their families to participate in an international exchange. A young EPP patient (20 years old) would like to visit the US in September. If you would like to be a host family, please let us know. Hosting involves only accommodation, all travel/food expenses are paid by a French donor. In turn, a French family will welcome and accommodate an EPP young person, too, but the patient must handle his or her own expenses in France. Let the APF know if you are interested in hosting a young person with EPP or if you want to go to France to be with a host family there. Call the APF 866.APF.3635 for more information and speak with Natalia.

Addison Says Goodbye to the Sun Whether old or young, EPP people spend their lives avoiding the sun. When the sun is out, they cling to shade trees, hide behind signs, wear layers of hot clothes and even jump between the shadows to keep the burning light from hitting their skin. Erica Kypreos posted this poignant photograph on the APF EPP Facebook group. It is of her little daughter Addison waving goodbye to the sun. Erica said Addison takes joy in heading to the park at sundown for an evening of play without her usual hats, gloves, extra sunscreen and layers of clothes.

Together we need to demand treatment so EPP kids can enjoy this beautiful world!

Letter to Congress Mike Kenworthy wrote the following letter to his Congressman and the FDA to enlighten them about Erythropoietic Protoporphyria (EPP) and the desperate need for the FDA to approve the Afamelanotide treatment. We need you to share your experience with the FDA and with your Congressmen, as well.

I suffer from an extremely rare disease known as a EPP, a severely photosensitive and phototoxic disease for which there is no cure and currently no approved treatment. Ironically, there is a proven treatment that is in compliance with Federal Drug Administration (FDA) clinical trial protocols including phase III, but for reasons known only to the FDA it has been languishing for 5 years waiting approval. I urgently need you help in this matter. Let me explain. EPP is an insidious trap in which I live. On certain days exposure to sunlight for brief periods of time, less than 15 minutes, can result in two to three days of excruciating pain, sleep deprivation, and loss of time on the job and income. Not only is this disease physically punishing, it causes deep depression and emotional trauma for me and my family. Simply put, it robs me of a portion of my life. Some EPP patients tragically die from liver damage. To the best of my knowledge, I am not one, but nothing is certain with this disease.

I have carried this burden since I was 4 years old. For more than 50 years, I have participated in every possible study and tried every "breakthrough" treatment. None provided any relief, and I have been resigned to live out my life in fear and pain. Then four years ago, I heard of a yet another clinical trial of a drug called Afamelanotide. Having been disappointed so many times, I was ready to write it off as another failure-in-the-making. It was a double blind test, so there was no guarantee that I would even get the active drug, let alone that it would produce any relief. But when there is no hope, one will grasp at any straw, and I became a participant in the FDA compliant phase II test. For the first time in my 60 years, I was able to participate fully in life like never before or since. If there existed a quality of life meter, it would have been pegged. To illustrate, for the first time in memory, I got sunburned, which is to EPP what a firecracker is to a nuclear device. It was uncomfortable for several hours, but I actually reveled in it. I was normal! For the entire 6 month period of the study I was able to do things that nature had forbidden me for more than a half a century of my life. Moreover, I was promised that I would be given a second year free treatment if the FDA would consent to compassionate use. I was ecstatic.

Then the FDA began the slow march to nowhere. First, the FDA refused to grant a waiver for compassionate use and indicated that they needed to see the results of a phase III study. I waited a year, then another. Nothing was forth coming from the FDA. They would not approve the phase III trial! A conference was announced for patients of rare diseases. However, for some reason only government personnel, some pharmaceutical companies and other functionaries were invited. Fortunately, Desiree, Director of the American Porphyria Foundation (APF), stepped in and made things happen as she is want to do. Mike and Steve Ferry, who also have EPP, and I were grudgingly allowed to attend.

We sat through nearly two hours of discourse on the illustrious history of the FDA and self-congratulatory exchanges between the FDA and NIH. When the floor was opened for questions, I went to the microphone and asked when we would get to discussion of what was being done to treat rare diseases. There was a pregnant pause, and the director came to the microphone and stuttered that we would get to that later in the afternoon probably hoping I would be gone by then. I stayed for another mind numbing round of meaningless talk. Finally, I was approached by FDA staff who appeared to be interested. It was as if they had never seen a real rare disease patient. Steve, Mike and I made our made my cases in very clear terms. The very next day, the phase III trial was approved, but it was already late in the spring, which would make it nearly impossible to pull together the logistics and find the requisite number of participants, after all this is not just rare but extremely rare. Maybe they thought this would end it. No such luck. With the help of APF, a consortium of porphyria experts who treat EPP, and the pharmaceutical company who manufactures Afamelanotide, Phase III was conducted.

The results of the phase II and phase III trials have shown with certainty (P>0.95) that the drug has no discernible negative indications and significantly improves the quality of life for most. It should be noted, that the mental scars created while living with EPP can never be erased. Despite the clinical data collected over 5 years and its use in some countries in Europe such as Italy and Switzerland, the FDA refuses to approve the use of the one thing that could give me back my life. They mumble about concerns of off label usage, which is conveniently overlooked when drugs like OxyContin are commonly used recreationally, and place emphasis on approving life enhancing drugs like Viagra and Cialis. I question their priorities.

We EPP "patients" are desperate for this treatment, which is already available to citizens of Switzerland and Italy, yet the FDA dawdles. Admittedly we do not represent a significant voting bloc. No one knows for sure, but there are probably less one thousand of us in the US. Still, we need you to intervene on our behalf so that we may gain access to this life altering miracle. Since safety and effectiveness have been clinically established, we see no reason we cannot have access to this drug.

Please contact your Congressman and the FDA. Tell them YOU demand a treatment TODAY!!!!!

Healthwell Foundation Offers Financial Assistance To Acute Patients We are pleased to join forces with the American Porphyria Foundation to increase porphyria awareness and spread the word about resources available through the HealthWell Foundation for people living with porphyria. Since 2006, the HealthWell Foundation has provided copayment and premium assistance to eligible acute porphyria patients. Through our fully-automated grants process, patients are able to determine eligibility and apply online. Patients also have the option to contact our hotline at 800-675-8416 to speak directly with a HealthWell representative. Learn more about the HealthWell Foundation: www.HealthWellFoundation.org

HEALTHWELL FOUNDATION®

FACEBOOK The APF now has over 1700 members in our FACEBOOK groups. If you would like to join in the discussions and porphyria news, find the APF open group, and the APF private groups for AIP, HCP and VP, EPP, CEP and PCT, as well as an EPP group for young adults. Porphyria friends from all around the world join together to communicate about porphyria and its effect on their lives. Join us at www.facebook.com/groups/AmericanPorphyriaFoundation/

Join Us At The FDA We are planning an FDA visit. If you are interested in joining a group of people with EPP to visit the FDA to once again meet with the FDA representatives to demand to know why Afamelanotide, the treatment for EPP, has not yet been approved, please contact Desiree at the APF. In early June the APF hosted three conference calls to discuss what has transpired over the last five years in the FDA approval process of the drug. Two of the calls were with the participants of the Phase II and Phase III trials with Afamelanotide. The additional call was with EPP members. Everyone agreed that the time is now to begin a major push for the approval of the drug.

Patients should not have to go without treatment for another year. However, although the APF can take the lead in this project, we need your help to move this project forward. As you read what Pierre did as one person, you can do the same and make something happen. Remember, Congressmen are our public servants. We are not their servants. Tell your experience like Mike Kenworthy shared his experience. Everyone has a powerful story. Now is the time to tell it. Tell it every chance you have. Tell it to the media. Tell it to your representatives. Tell it to your doctors and friends. Tell it everywhere. There is no good reason that you should not be receiving that treatment to end the suffering of EPP. And if you want to join us at the FDA, please contact Desiree at the APF.

Oliver's Medical Journey *Since the day he was born, our baby Oliver Stanek has been through more than most of us have in our entire lives. Without warning, I was told that Oliver needed to be born early due to complications with little to no amniotic fluid. Neither we nor the doctors had any idea what was ahead of us. Oliver was born at 35 weeks, on November 14, 2012. At first glance, we thought nothing was wrong. He looked healthy but within 24 hours, Oliver had renal and liver failure and his bilirubin was off the charts. There is nothing worse than the thought of losing your child. Over four days, Oliver started healing himself. Words cannot explain our joy. The doctors were baffled. Finally, after two and a half months spent in the NICU, he went home and was treated as an out-patient. Since then, Oliver has been suffering from frequent blood transfusions and multiple skin lesions yet he is calm and happy. After eight months, the mystery began to unfold. Oliver was diagnosed with Congenital Erythropoietic Porphyria (CEP), which is ultra-rare with only 250 reported cases. CEP causes porphyrins to build up in the bone marrow and skin, causing shortening of life of red blood cells and extreme photosensitivity to sunlight and artificial light. In some cases, it is known to affect the liver and kidneys, as well. Now we understood why Oliver was severely burned on the whole left side of his body from the phototherapy he was given to decrease his bilirubin. He also suffered from multiple bone fractures due to vitamin D deficiency.*

On October 17th 2013, Oliver underwent bone marrow transplantation to cure his disease. He passed through chemo with flying colors! Unfortunately, he is still very red cell transfusion dependent. The doctors fear that Oliver may be rejecting his graft, or the graft is not working. Because of the many transfusions Oliver has needed in the past months, his liver has been greatly impacted. In order to receive a second transplant, he will have to have chelation therapy that could last a couple of months. We are in high hopes that this second transplant is as easy as the first one. Please join us in praying for a better overall outcome for Oliver.

We thank Nichole Zimmardo, Oliver's mother, for such a poignant article and expert, Dr. Joseph Bloomer, for his medical expertise. See Oliver's Medical Journey: http://www.youtube.com/watch?v=KEBpLp9Jz8c

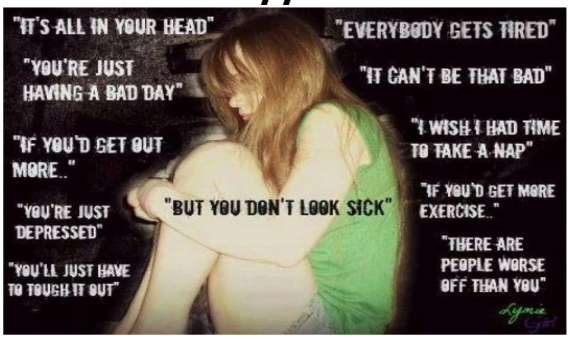
APF Pain Project The APF has initiated a *Pain Project* to assist the many porphyria patients who are not receiving appropriate pain treatment. We initiated this project in the state of Florida because of the many pain treatment problems that have occurred since Florida began passing strict laws concerning specific pain medications. Because of these laws, we will be expanding this pain project throughout the country. We need your help. If you have encountered a problem receiving appropriate pain treatment or have been placed in a demeaning position over the use of pain medication during an acute attack, please contact Desiree at the APF and share your experience. At present, we are approaching state legislators and health departments, as well as most well-known pain experts to assist us in this endeavor. In addition, Dr. Lisa Kehrberg will be sharing her experience with AIP, including an in depth explanation of a porphyria attack and the pain that follows. View the video of Dr. Kehrberg on the home page of the APF website: http://www.porphyriafoundation.com

Two Young EPP Friends Meet Recently, two young girls with EPP met in Memphis and made fast friends. Madelyn Havard (L) from Memphis and Savannah Fulkerson (R) from Los Angeles shared their experiences with EPP.

Savannah said: "It was great to meet someone with the same disease that I have. It was nice to talk to someone who knew what I was going through and not have to explain it to her. And not have somebody ask me 100 questions about why I can't be in the sun. We talked about what sports we like to play." Madelyn added: "I had so much fun meeting Savannah. It was really neat to have a friend to talk about EPP with. We showed each other pictures our moms took of our sun reactions and we showed each other clothes we use to stay out of the sun. It was fun to have someone that wants to swim when the sun isn't out too. I can't wait for Savannah to come back to Memphis for a visit."

Both girls enjoyed making a new friend, especially since they had so much in common. Their moms had met on the APF EPP FACEBOOK group and began communicating. When they discovered that they would be near each other this summer, they jumped at the chance for the girls to meet. Watching younger an older people making friends is a delight. We hear such wonderful stories of people learning from one another and just enjoying meeting others with the same condition. But when kids can meet, that is the greatest joy. You can tell from the photo that these two girls are thoroughly enjoying knowing one another. If your child would like to have a pen pal or meet a friend with porphyria, please contact the APF. We will help them find each other. Kids need to communicate, too.

Has It Ever Happened to You? Tell Us About Your Experience



It is all in your head. Shall I make you an appointment with a psychiatrist? You're just having anxiety. The pain can't be that bad. Rest more and you won't have such severe symptoms. I have pain like yours, but I gather my own strength and take it. Try biofeedback.

These are all hurtful and often demeaning responses that many of us have heard from doctors and other medical professionals. The best way to combat this is patients to be tested properly and treated appropriately. Please help us increase awareness through physician education efforts. The APF maintains a large Physician Education Program, but this program needs your help. We need your financial support to distribute porphyria medical materials, doctor packets and to fund educational presentations. Please mark your donation, PHYSICIAN EDUCATION PROGRAM. You can also help heighten awareness in your own communities. The APF will provide materials for your awareness activities: 866-APF-3635.

🕊 *In Memory*

We are saddened to hear of the passing of dear family members and friends. Some of you have chosen to honor a life by making a gift to the APF to help others with porphyria. Please join us in thanking:

Marguerite J Nelson, Maryellen and Rena Lagerblade, Peter C Noyes, Richard and Carol Lincoln, Robert W Wright, Marshfield High School, Marshfield School Committee: Marti Morrison, Carol Shrand, Nancy Currie, Denis Scollins, Richard Greer, Governor Winslow School for ***Robert "Bob" Quigley, Jr.***; William Rickert for ***Gina Marie Opperman***; Susan Rutherford, Alice W Cothron for ***Joyce Elaine Weiss***; Carole E Kuklewski for ***Vincent Kuklewski***; Mary P Crown for ***Mary B Hargett and Dean Puccia***; Dr. Susan Engel-Arieli for ***Lee Engel***; Michael O'Connor for ***Mickey O'Connor***; St. Vincent De Paul Regional School, Linda M Pirolli for ***Dorothy Gardner***; Gary Horn for ***Sandra Horn***; Randall and Patricia Valli, Debra Seymore/The Fl League of Cities, Greg and Debra Humphries, Mary B Ward, Desiree Lyon Howe, APF FACEBOOK administrators for ***Grace Warfield.***

🕊 *In Honor*

We also thank those who donated to the APF in honor of friends and family members.

Claudette M Owen, Jan Marsh, Susan Edmonds, Vernon Middle School, Mrs. Jimmy Ray Carr, Teresa C Ansley, Donna H Lorance, Shive Elementary School for ***Cason and Caul Cook***; Valierie A Delazaro for ***Tracy Yelen and James Young***; Fred Cerkoney for ***Stephanie Cerkoney***; Susan Frison for ***Connie Helleson***; Ian Gray for ***Ralph Gray***; Vincent Polio and Donna Malone for ***Candace Johnson***; Larry and Joyce Gilles for ***Janet Gilles***; Lloyd and Marlene Ankeny, Judy and Frank Coelho for ***Jennifer Blackburn and Connie Helleson***; Teena and Craig Rasmussen for ***Jennifer Blackburn***.

Grace Warfield was a longtime member of the APF and a great friend to our staff and her many friends with porphyria. Grace was one of the many people who had a terrible experience with medical care. Not only did she suffer from acute porphyria, she also had to battle to receive appropriate treatment. Grace was a wonderful person. When she was able, she manned the booth for the APF at medical conventions, helped us create APF banners, hosted a "fun run" to help raise donations for the APF physician education programs and awareness of the disease. Grace tried fervently to change the world of porphyria for herself and the others who suffer from the porphyrias.

Grace had an early career as a model and then moved to Orlando where she played Pluto at Disney World. She was a team member that built the *Tree of Life* at the Disney Animal Kingdom and followed by a career in marketing when she began a downhill cycle of illness. Grace sadly died from complications from porphyria. We extend our sympathy to her parents, Rose Mary and Robert Warfield, sisters, Leann Brezinsky and Beverly Boesch, and brother, Robert. **Those of us who work with the APF office become close with many of our members and are saddened by the loss of all of our friends.**

Volunteers Needed: American Association for the Study of Liver Diseases (AASLD) will host their annual meeting in Boston Nov 7-11, 2014 at the Hynes Convention Center. More than 9,500 hepatologists and hepatology health professionals from across the nation and around the world will gather to discuss the latest in the field. The APF will have an exhibit booth to distribute porphyria medical information and promote porphyria awareness. We need volunteers to help man the booth. You will be meeting with the physician attendees, handing out educational literature, and sharing your porphyria experience with the doctors who come to the APF exhibit booth. If you live in the Boston area and are willing to assist us by manning the exhibit booth, please contact us: 1.866.APF.3635 or porphyrus@porphyriafoundation.com

Volunteers Needed: The American Society of Hematology (ASH) The Society will host its 56th Annual Meeting in San Francisco, CA, December 6-9, 2014 at the Moscone Convention Center. More than 20,000 hematologist and health professionals in the field will be in attendance. These conventions provide an excellent opportunity for the APF to educate physicians who will be treating porphyria patients. The APF will also have an exhibit booth at the ASH convention, as well as the AASLD. If you live in the San Francisco area and are willing to assist us by manning the exhibit booth, please contact the APF.

You Can Attend Patient Educational Meetings The APF will be hosting patient meetings in conjunction with the above mentioned meetings and throughout the US. These meetings provide patients with the opportunity to hear experts give presentations on each type of porphyria, meet others with the same type of porphyria and share in a questions/answer session. People who have attended the meetings have told us that they have learned more about porphyria by attending than any other means.

Follow our weekly e-news to be aware of the time and places. Some of the cities include: San Francisco ,CA, Boston, MA, Santa Rosa Beach, FL, Los Angeles, CA, Atlanta, GA and Chicago, IL. Everyone is invited. Come and Learn!! Come and Share!! Come and Enjoy!! If you would like to help with the meeting by serving as a greeter and organizing the tables, seating etc, please contact the APF.

Comprehensive Packets for You and Your Doctor

Below are the components of the comprehensive doctor's packet we send out to your physicians. In addition, we also have a patient's packet with the following components:

Physician Packet

Annals of Internal Medicine
"Recommendations for the Diagnosis and Treatment of the Acute Porphyrias"
Brochure on Management of Acute Porphyria
Panhematin brochure
Overview of all porphyrias
CME courses brochure
Safe unsafe drug list URL
Emergency room guidelines
Pain letter from expert Current newsletter

Patient Packet

Overview of all porphyrias
Panhematin brochure
APF Newsletter
The APF membership information
Letter from Desiree Lyon Howe to patients
How to become an APF Member

All educational materials are written by porphyria specialists. The APF will gladly send you and your doctor one of these complimentary packets. Please contact us at 713.266.9617.