



## SEASON'S GREETINGS FROM THE APF

The APF staff is blessed to serve this community.  
Thank you all for your kind and generous support in 2017.  
May 2018 be a year filled with health and wellness for each of you.  
With love, Desiree, Kristen, Edrin, Yvette, Susan, Amy and Rob



## 2018 HEME BIOSYNTHESIS AND THE PORPHYRIAS: RECENT ADVANCES SCIENTIFIC CONFERENCE and CLINICAL DAY FOR PATIENTS JANUARY 12-14, 2018 in ORLANDO, FLORIDA

**CALLING ALL DOCTORS AND PATIENTS!** The Porphyrias Consortium and The American Porphyria Foundation are excited to host this important scientific conference and clinical day for patients. The three-day symposium will focus on the most recent findings on the molecular biology and regulation of heme biosynthesis and the clinical features, pathophysiology, and current treatment of the acute hepatic and erythropoietic porphyrias. This symposium is open to all healthcare professionals including clinicians, researchers, nurses, genetic counselors, Junior Faculty, Pre/Post-Doctoral students, fellows and medical students, who will earn up to 25.5 CME Credits. The APF would be pleased to send your doctor additional information and a personal invitation!

The Clinical Day for Patients will offer in-depth presentations on Porphyria. Patients will have access to international experts, including discussions and an interactive Q&A session. Patients will also have an opportunity to meet and greet with fellow APF members. What a wonderful opportunity! For a detailed agenda and to register for this event: [www.porphyrissymposium.com](http://www.porphyrissymposium.com). We look forward to seeing you there!

**PORPHYRIA PAIN PROJECT** With the recent crackdown on opioids for pain, many patients have been put in the terrible position of having their pain meds monitored to the extent that they cannot access them timely. As states have tightened their requirement regarding pain medication, porphyria patients are paying a terrible price for the misuse of other people. For example, chain CVS Health announced that it will limit opioid prescriptions in an effort to combat the epidemic. They said they will limit initial opioid prescriptions to seven-day supplies for new patients facing acute ailments. Although this may appear good for one group of people, it is devastating for those people with porphyria who are



suffering attacks or chronic pain. The APF has undertaken this enormous project—advancing awareness and understanding of porphyria pain among physicians and among state medical boards, state health departments and the CDC. This is the most important issue that has faced our patients in many years. Preeminent pain expert and internationally recognized neuro-oncologist, Dr. Kathleen Foley, is passionate about her work as a pioneer in the battle to avert needless pain and suffering and management of acute pain during the treatment process. Dr. Foley is recognized worldwide for her extraordinary pain relief work and her focus that governments must not limit a physician from treating real pain. The APF will be using much of her research and educational materials in the development of our PORPHYRIA PAIN PROJECT FOR PHYSICIANS and state health departments. She and other pain experts have addressed the issue that drug abuse has hindered the need of people who are suffering badly both physically and emotionally. The APF will be distributing pain materials for physicians and hospitals, contacting state and national Health Departments, advancing awareness of porphyria pain at medical meetings and conventions and other national efforts. ***Please help by sending your story of your pain management being taken from you in whole or part. We will only use your initials and not your full name.***

**FACEBOOK SUPPORT GROUPS** The APF moderates eight Facebook support groups. There, you will find peers who have been diagnosed with Porphyria and information that will always be scientific and approved by an expert. Search for Porphyria – American Porphyria Foundation. The APF Director of Social Media, Amy Chapman, will be happy to help!



## MEET OUR NEW **PROTECT THE FUTURE DOCTOR: DR. BEHNAM SABERI**



Dr. Saberi, Hepatologist, works in the liver division at Mount Sinai Hospital in New York City. He did his transplant hepatology fellowship at Mayo, Rochester in 2014 and from 2014-2017, Dr. Saberi was on the faculty at Johns Hopkins. He then joined Mount Sinai in August 2017 and currently works in clinical and translational research in hepatocellular carcinoma. Dr. Saberi is excited to be part of the Porphyrrias Consortium and be involved in our studies and clinical trials. He is also looking forward to his participation in the APF *Protect the Future* program as one of the next generation of porphyria experts. Please join us in welcoming Dr. Saberi. We look forward to his involvement with the APF and our members for years to come!

**WHAT IS THE *PROTECT THE FUTURE PROGRAM*?** Think of it this way!!! When our present experts retire, who will write the medical text books that our primary care physicians read to learn about porphyria? Who will consult with our primary care doctors when they don't know how to save your life? Who will perform the life changing and life-saving research that provides hope for the future for improved treatment and a cure? NO ONE WILL. HOW CAN WE PROTECT OUR FUTURE unless we train young doctors and not lose the expertise of our present experts! The *Protect the Future* program trains the next generation of experts. We have now trained twenty-five young doctors with more to come. But it takes funds to train doctors. It cannot be accomplished without your help as you are the ones to benefit. Here is what we will do.

**Goal 1:** Train more physicians and scientists to become academic leaders in both the clinical and basic science aspects of the porphyrias

**Goal 2:** Provide training for primary care and specialist physicians to advance knowledge of appropriate diagnosis and clinical management services to a widespread population of Porphyria

**Goal 3:** Include all PTF doctors in the publications, research, abstracts, posters and similar activities

**Goal 4:** Include all PTF doctors in national and international conferences and involve them as presenters

**Goal 5:** Establish satellite centers identified as porphyria clinics with PTF physicians as directors

## **WHEN YOUR DOCTOR WON'T TREAT YOU** Before you do anything, print out the Tool Kit

 found on the APF website. Many of our members have reported that their physicians will no longer treat them for porphyria once diagnosed, or they can't find a doctor. According to prestigious journals, like *JAMA* and *Annals of Internal Medicine*, a good physician/patient relationship is central to the practice of good medicine! Most medical schools teach students to maintain a professional rapport with patients, uphold patients' dignity, and respect their privacy. They contend that the better the relationship in terms of mutual respect, knowledge, trust, shared values and perspectives about disease and life, and time available, the better will be the

amount and quality of information about the patient's disease. This will enhance accuracy of diagnosis and increase the patient's knowledge about the disease. It is not just up to the doctor. A patient must also take part to build a trusting bond. Below are ways to improve your doctor's visits and relationships:

\***Research** your physician so that you choose the right one for you. Doctors may have never had a porphyria patient but sometimes you may find one with this experience. Call the APF for help. We cannot validate the expertise of a physician, but we have had patients share their doctor with us and we will share them with you.

\***Be prepared** ahead of time with your list of questions and keep them very concise. This is the best way to show your doctor that you understand and respect his/her time constraints.

\***Be direct** about your health situation and not chat aimlessly. Rather, briefly mention something friendly to lighten the visit. Doctors spend their whole day under stress and time limits, so breaking that tension might be just what it takes to lighten the moment.

\***Ask questions** and don't be afraid to speak up and ask your doctor to explain his comments.

\***Take notes** and bring them home. Write down the medication instructions and ask for brochures or other educational materials if they are available.

\***Do not bring** materials printed from the internet. Most doctors read prestigious medical journals. If your doctor has not received the physician packet, please call or email the APF with your doctor's contact information.

\***Advise the doctor** of the APF physician packet and the Health Professional Section on the APF website.

\***Tell your doctor** about any current and past health care concerns, past health history, recent tests, x-rays, pertinent information, and your current medications, vitamins and supplements.

\***Thank your doctor** if you feel you've experienced that compassion and friendliness you've needed. Sending a hand-written note is particularly thoughtful.

**THE APF MEMBER DATABASE NEEDS YOUR HELP!** Do you have a child with Porphyria who is now over 18? They can now receive our communications directly. Please have them contact the APF office on 866-APF-3635 or email [edrinw@porphyriafoundation.org](mailto:edrinw@porphyriafoundation.org) to update their contact information.

## **GIVOSIRAN PHASE III CLINICAL TRIALS**



Alnylam Pharmaceuticals is currently seeking participants for the Givosiran Phase III Clinical Trial which is set to begin in late 2017. Over 70 participants are needed for this randomized, double-blind, placebo-controlled study, which will be followed by Open-Label Extension. To qualify, patients must be 18-years of age or older,

have had 2 or more attacks in the previous 6 months, and be willing to discontinue and/or not initiate hemin prophylaxis. If you want more information on this clinical trial, please contact the APF on 866-APF-3635 or email [edrinw@porphyriafoundation.org](mailto:edrinw@porphyriafoundation.org)



**MICHAEL BOONE** After four years of searching, in 2008 I was finally diagnosed with Acute Intermittent Porphyria. At the time I had no idea how it would affect not only my life but that of my wife, children, and even my parents. I worked in my family construction company while wearing an ambulatory infusion pump, and also had up to four infusions of Panhematin a month. As time progressed I began missing more work until I just couldn't do it anymore and applied for

disability. I was approved on my first application - I suspect it was my medical records that amounted to reading three very long novels. I figure somebody decided they weren't going through all that and just stamped approved! I had hoped that things for me would improve after stopping work but, they didn't. I had nearly constant chronic pain and was on three different pain medications. I also had chronic nausea and at one time I was on four different medications, including one IV medication.

I was in the longitudinal study where I got my DNA confirmation. I also participated in a Panhematin study and the natural history study that led me to being a part of the Givosarin trials. I highly recommend you participate in all the studies that you can because it can lead to you getting ground-breaking treatments. In early 2016, I was chosen to be a part of the double blind Givosarin trial. I will be the first to admit that the double-blind portion of the study was very hard. There were four of us and one of us had to have a placebo as a control. It was me. There were a few times I was extremely sick and had serious thoughts of backing out but, I knew that the next phase was an open label and I would be getting the real drug. Now, I am getting the real drug and my life has changed dramatically. When I was sick my wife did not have a husband and my children didn't have their father. As I write this I'm on a flight to Houston and I feel wonderful. I started back to school to get my EMT basic certification again. I will do that part time until the drug is approved and I can reliably get the medication. I will say that the end of the three years of the open label extension study terrifies me. I don't want to go back to being sick I honestly don't know how I will handle that hell again. I have faith though that God will see me through and give me nothing I can't handle. I will gladly fly to Houston once a month and get the injections. By the way, if you are afraid of needles, don't worry; it's about the same size as an insulin needle. Best of luck to you all, I hope your health is good.

## **KRISTEN STEINHILBER MCGLAUGHLIN**



I am an AIP patient who was diagnosed five years ago after suffering acute attacks for several years. I feel fortunate to have participated in the Givosiran Clinical trial and I am currently in the Open Study. The therapy has changed my life SO MUCH (and my family's, too!). It has allowed me to regain a quality of life and didn't think would ever be possible. Having porphyria is an incredibly difficult journey but I've been lucky to have amazing care the entire time - from diagnosis, heme therapy and ongoing treatment,

even at my sickest points. I'd love to do what I can to give back to the community now that I'm feeling so much better and have energy. I am happy to talk to any APF member who is considering participating in the upcoming Phase III clinical trial to share my experience.

## **E-DIARY PATIENT INTERVIEW STUDY**

There is study in progress regarding a newly developed Porphyria electronic diary. The APF reached out to members with Acute Hepatic Porphyria (AIP, HCP, VP and ALAD) to participate – and received a fantastic response! The study is researching how both patients and caregivers respond to the online diary. There are many ways to participate in research and we thank our members who responding to the call to share their experience in this way!

## **WHAT GENETIC WEBSITES DO THE EXPERTS RECOMMEND?**

The following websites are recommended by Dr. John Philips, member of the Porphyrias Consortium, for good explanations on the basic science of genetics and mutations. Read and learn to advance your knowledge about the basics of Porphyria!

Basic genetics: <http://learn.genetics.utah.edu/content/basics/>

Mutations: <http://learn.genetics.utah.edu/content/basics/mutation/>

Dominance/recessive: <http://learn.genetics.utah.edu/content/basics/patterns/>

Genetic variation: <http://learn.genetics.utah.edu/content/basics/outcome>

**HEALTH PROFESSIONAL RADIO INTERVIEW** Desiree Lyon Howe, APF Executive Director, was given the opportunity to enhance porphyria awareness by participating in a live radio interview with Health Professional Radio. Desiree spoke on the acute hepatic porphyrias, raising patient and physician education, awareness, misdiagnosis and much more. Health Professional Radio is an online radio/podcast network targeting 35K global healthcare professional listeners with a focus on "news and talk" geared toward a range of healthcare professionals across specialties and with a range of clinical experiences (including residents, nurses, and MDs). The show includes interviews with experts and everyday people on important health topics; some content is clinical, some management orientated, and some lifestyle orientated. Listen to the interview here: <https://healthprofessionalradio.com.au/american-porphyrina-foundation/>



**NORD RARE DISEASE SUMMIT IN WASHINGTON, DC** The National Organization for Rare Disorders held an annual summit in Washington, DC on October 16-17. Kristen Wheeden, Director of Development, used this opportunity to represent the American Porphyria Foundation in the larger rare disease community. There are 7000 known rare diseases and 450 orphan drug designations, but only 5% of rare diseases have an FDA- approved treatment! This event brought together key stakeholders for open and collaborative discussions on the latest updates, treatment technology and emerging trends in patient care. The summit featured the updates from the FDA as leading Division Directors took center stage during an engaging plenary session. It was a great opportunity to network with fellow advocates, industry leaders and researchers – and to make sure that the APF is in the center of it all.

**#PORPHYRIASTRONG** **APF FIGHT THE STIGMA CAMPAIGN** Recently we have been focusing on physician education as a step to take in order to combat the issues with stigma that many of you face on a daily basis. Self-advocacy and communication are vital steps towards breaking the barriers to discuss the stigma that is associated with Porphyria. As a next step, we are asking you to share your story about Porphyria. Include that you acknowledge the presence of the stigma, negative factors that contribute to the stigma and what can be done to reduce it. Writing down your thoughts and sharing them with your physicians, family and/or friends will encourage others to do the same. Once you write your story, send it to Edrin Williams ([edrinw@porphyriafoundation.org](mailto:edrinw@porphyriafoundation.org)) at the APF office for a chance for your story to be featured on our APF Website, 2018 Q1 – Newsletter and Porphyria Post. Join the fight. YOU have a voice, and it matters. **We are Porphyria Strong.**

**FIGHTING ISOLATION BY APF MEMBER SHARON DILL** Acute Porphyria can be very isolating, causing patients to withdraw from social interactions. As Depression can be one of the many —side effects of this already debilitating condition, it is essential that patients fight hard to stay connected to family and friends. I have Variegate Porphyria and know first-hand how difficult it can be to maintain any type of relationship, much less nurture them. It can be embarrassing to cancel at the last minute over and over, so it sometimes easier to just decline an invitation. And then the invitations stop coming and isolation becomes your new normal. We must fight those instincts and find the strength, energy, and courage to stay engaged with our friends, family and communities. Humans need face -to-face communication. We need to have personal physical contact – shake hands, hug loved ones, hold the hand of a friend. Those with chronic, debilitating diseases perhaps need it even more. It is hard work, but it can be done. Perhaps not with the same frequency as before our illness, but hopefully with at least the same quality. Planning is important. Advanced planning, whether to meet friends for lunch or travel cross country for a family reunion, can enhance your visit and make the time together even more enjoyable. Good planning starts with good communication. Make sure your friends and family know that you are looking forward to seeing them and will do everything you can to be up for the visit, but Porphyria sometimes has a mind of its own. Most of us know our bodies and generally know if we do better in the morning, afternoon or evening. For me, evenings are tough due to low energy and nausea. For these reasons, I try to plan later breakfast or lunch get-togethers. They may be willing to meet at a location closer to your home. Hosting get-togethers at your house will eliminate the need for travel, but can increase the amount of work you have to do. So instead of your usual six course culinary masterpiece, ask everyone to bring something or order take out. Your friends may love your cooking, but the real reason for the visit is to spend time with you. There are many ways to fight isolation and it is important that you find ways that work best for you!





## NICOLE CASTELLANO IS OUR AMAZING APF ATHLETE!

Just a few short years ago, Nicole was bound by a wheelchair and suffered three near death experiences related to her AIP. This October, Nicole successfully ran the 40<sup>th</sup> Chicago Marathon - she also spread awareness about Porphyria to thousands AND raised over \$4600 for physician education efforts. After her video, interviews and articles, the number of APF Twitter followers jumped to 11.8 thousand and APF YouTube subscribers to over 2,000!! Each step of her journey and each mile she ran helped to support all who are living with Porphyria.

CONGRATULATIONS, NICOLE, AND THANK YOU FOR TREMENDOUS SUPPORT! THE APF IS VERY PROUD!

## VITAMIN SUPPLEMENTS EXPLAINED by Purple Light Blogger Amy Chapman



APF members have expressed interest in knowing what vitamin supplements are good to take. The FDA does not regulate vitamins, supplements, any OTC products or foreign herbs, oils etc. With that in mind it is critical to ask your physician what is a good recommendation for you if you need vitamins or supplements. For most Americans who are consuming mixed, well-balanced diets, there is no need for routine use of vitamin or mineral supplements. Persons who consume few dairy products [milk, yogurt, cheese, etc.] and older persons, especially women, and those with

little exposure to sunlight are prone to develop deficiencies of vitamin D and to have inadequate intake of calcium. Thus, they should seek advice of a well -trained physician or nutritionist regarding supplements of vitamin D and calcium. Iron may trigger or worsen porphyria cutanea tarda, and it may also increase levels of hepatic ALA synthase 1. In addition, herbal remedies and dietary supplements (HDS) have become popular in the USA and in many other parts of the world. Please note, they are unregulated by the US Food and Drug Administration, and they have not been shown to be safe and effective. Please consult your physician if you are considering vitamin supplements.

## PATIENT EDUCATION AND SUPPORT MEETINGS

On Saturday, September 16, 2017 the American Porphyria Foundation hosted a Patient Education and Support Meeting in Anaheim, CA. This meeting was facilitated by Edrin Williams, APF Director of Patient Services. When hosting these meetings, it is our hope to make it a place to provide valuable information, and share common concerns and issues amongst each other. Getting together in a group/social atmosphere helps individuals realize that they are not alone and provides the opportunity to be with each other. The

meeting began with a short presentation about the history of the APF, current projects the APF is working on and research efforts. There was a presentation by Jordanna Mora, Associate Director of Patient Advocacy and Engagement, Alnylam Pharmaceuticals, followed by a question/answer session with Porphyria Expert, Dr. Karl Anderson of UTMB, Galveston, Texas. There were close to 30 patient members, family and friends in attendance for this event. If you are interested in hosting a meeting, please contact Edrin or Yvette at the APF office and they will help you coordinate your efforts. The APF will supply the invitations, educational material and set up a speaker. We need YOU to host in your community. Call the APF to get started!

## GLOBAL GENES GALA

On Saturday, September 16, 2017 Global Genes hosted a Tribute to Champions of Hope Gala in Anaheim, CA. Edrin Williams, APF Director of Patient Services and local porphyria patients were invited to attend this event by Recordati Rare Diseases, Inc. This annual event brings together patients, advocates, health care partners, industry leaders, celebrities and many more who #CareAboutRare. Those honored at this event are doing remarkable work to raise awareness, support, and develop lifesaving therapies. Seeing

everyone come together as one community really brought hope to those in attendance. Thank you to Harry Struppa, Molly Buffington and Nancy Downes for your attendance in this event. Pictured (left to right): Edrin Williams and Lynne Angell, Senior Product Manager, Marketing and Advocacy, Recordati Rare Diseases, Inc.



**Don't Forget Your Medic Alert Bracelet and your APF Warning Card for Acute Porphyrias**



## SHADOW JUMPERS: A NEW PROGRAM FOR CHILDREN WITH EPP



The upcoming Shadow Jumpers Project was initiated by Craig Leppert in partnership with the American Porphyria Foundation. Craig was diagnosed with EPP at a young age and grew a love for overcoming the sun to do anything and everything outside. Defying that outdoor adversity led to Craig and his family to being featured on national programs such as the Dr. Oz Show, Mystery Diagnosis,

ABC News and numerous print publications. Through that spotlight and being one of the first test subjects in the Afamelanotide trial, Craig was able to connect with many EPP patients and hear their stories. It troubled Craig to see so many people letting the sun and EPP dictate their life. Young people were abandoning any thought of pursuing dreams, adventures, careers or even relationships out of the fear to what would happen to them. Craig, who graduated from Syracuse University and now resides in Los Angeles, developed the idea of the Shadow Jumpers Project to encourage young people with EPP to overcome the sun to do anything they've always wanted to do. The Shadow Jumpers will feature information and programs geared toward our youngest members. Stay tuned!



### **GREGORY EDWARDS, Hereditary Coproporphyrria (HCP)** I was

15 when I noticed my first issues and I thought I just had a bug. I started to get electric shocks shooting throughout my body in my muscles and my bones. Things were fine until my junior year when the shocking was so bad it would scare other kids in class with my jumping and jerking. It would bring tears to my eyes. My first trip to the ER was after collapsing in Trig class. Of course, every test was normal and since I

was a poor kid no doctor wanted to pursue anything. I noticed that when I was weak I had more abdominal pain and I would swing back and forth between severe constipation and diarrhea. Over the next ten years I would go through these bouts. Things were better after college; I was less stressed. As time went on and I had to go back to school, I was not sleeping well and not eating. My symptoms came back with a vengeance. I was diagnosed with small fiber peripheral neuropathy. I had to use crutches and canes to help me walk. MRIs of my brain showed holes that would come and go in size and shape. I started having seizures. My leg weakness was so constant I started to use an electric wheelchair. I eventually moved again to be a college professor of anatomy. I was out of the wheelchair at that time and felt excited to be doing what I wanted, and as a result I started to ignore my health. Everything made me nauseous and caused vomiting. My abdomen was in constant pain and I ended up back in my wheelchair and having seizures. I was let go from the college. I am on federal disability now still in pain, still having seizures (even yesterday in the doctor's office, I had three seizures and collapsed in the ER), still getting weak and damaging my muscles, still sick from eating certain foods. Three years ago the term Porphyria was first mentioned to me as a possible answer to my years of suffering. I always felt sick so it was hard to get the samples during the worst part of an attack. When I first got a good result my doctor told me it seemed likely to be Porphyria, but more testing was needed. It was confirmed to be Hereditary Coproporphyrria. Education is the best defense against the ignorance that leads to 25 years of suffering!



### **TEEN WITH EPP WORKS IN GEORGIA TECH LAB** Hannah Watkoske, 18,

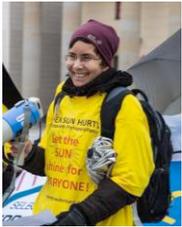
was diagnosed with EPP at age 3. Throughout school, she has had a great interest in science. A friend from NIH coached Hannah and through a class in Independent Science Research at her high school in Atlanta, GA, they found Dr. Amit Reddi at Georgia Tech University. Dr. Reddi offered Hannah to work on an existing experiment in his lab. Her

project is related to how heme is sent throughout the body at a cellular level. The goal is to determine the rate of heme synthesis and where it is occurring in the cell. Through her work in the lab, Hannah studies science and contributes to her own rare disease! She worked every day in the lab over the summer and is there three days a week during her senior year. When she isn't in the lab, Hannah volunteers for the Service Leadership Board at her school (most recently organizing a blood drive!). She also plays the violin and volunteers for the local Boys and Girls Club. We wish Hannah the best of luck as she graduates in May 2018!

**Remember to visit the APF STORE on the American Porphyria Foundation website.**

**T-shirts, sweatshirts, bandanas, wristbands, baseball hats and more!**

<http://www.porphyrifoundation.com/content/apf-merchandise>



## MEET DR. JASMIN BARMAN: EPP patient, porphyria researcher and patient

**advocate.** Like most EPP patients, it took a long time between the first phototoxic reaction at age 2.5 and my diagnosis. One night after a bad reaction in spring 2006, I got up and searched the internet for an explanation to my strange “sun allergy.” Excitingly, I found a new article, with the unfamiliar title — Erythropoietic Protoporphyrria. Eight sentences written in lay terms just two weeks earlier by the beloved founder of the German EPP patient organization described my life – and changed it in a way I would never have guessed. Today, I am in charge of the laboratory conducting all porphyria diagnoses in

Switzerland, act as scientific advisor for the Swiss Society for Porphyria, am a co-founder of the International Porphyria Patient Network and represented the patient perspective during the approval process of afamelanotide (Scenesse®) at the European Medicines Agency (EMA). After finding out about EPP, it was overwhelming to meet other sufferers for the first time. It is impressive to see how similar the experiences and coping strategies of EPP patients are. Since the majority of people around us do not believe how painful EPP is and how much it restricts all aspects of daily life, we tend to hide the condition and try to find our own ways in this world poisoned by light. I was fascinated to learn about all the aspects already known about EPP, like the fact that visible light is causing the phototoxic reactions and not UV radiation: finally an explanation of why sunscreens never helped! I was intrigued by the many things not yet understood about EPP. So you can imagine my excitement, when Dr. Elizabeth Minder offered me a PhD position in her lab in Zurich! My main area of research became iron metabolism and gene regulation in EPP. Because of EPP, I will never be the outdoor biologist catching new species in the mud of a tropical rainforest that I always wanted to become. But because of the condition I got to know so many great people in the patient and research community, found a fascinating research area and witnessed the development of a new drug! I am looking forward to the many exciting new developments in the field of porphyria and hope to meet many of you in January in Orlando!

## DR. AMY DICKEY, PULMONARY ICU SPECIALIST AND APF MEMBER



Although medical school taught me about human disease, it somehow made me even more uncomfortable with the idea of having one myself, especially an inborn error of metabolism such as EPP. It has now been over 20 years since my diagnosis. Still, few of my friends or co-workers know anything about it, having no suspicions as to why I might decline certain outdoor invitations. For anyone with EPP, it probably does not come as a surprise that my physician friends are initially no more likely to understand EPP than non-physicians. On top of that, it has been a sensitive topic for me, still with plenty of memories of the pain and isolation that I felt in childhood. After yet another EPP reaction this past summer, though, I realized how selfish I was being. Because of my secrecy, it may be my own friends and co-workers who miss a diagnosis of EPP, leading to a delay in diagnosis for someone else. I do not want that. I now feel ready to use my platform as both an EPP patient and pulmonary critical care physician at Harvard’s Massachusetts General Hospital for the purpose of advocating for EPP patients and for the approval of afamelanotide. Yesterday, I went to a porphyria patient meeting in Bethesda, MD, for the first time meeting other patients with EPP besides my brother. It brought up many emotions for me that I do not know how to name yet. All I can say is that I now feel blessed to be finally connected to my porphyria family.

## IN MEMORY AND IN HONOR

**In Memory:** We thank the families and friends who honored their loved ones with a generous gift to the APF. Marylou and William Rickert for **Gina Marie Rickert Opperman**; Michael L Hammond, Sheila and Richard Meltabarger for **Ingo Lehmann**; Kathleen Toelkes for **Donna Pagano**; Joyce E Falkenbury, Richard and Alice Rezabek, Victoria and David Snide, Rose Lilly and Norman Korniak, Vincent Palacio, Jr., Sandra L Roosa, Suzanne and Thomas Morse for **Donald McLean, Jr.**; Charlotte J Beck for **Elva Denger**; Connie and David Corbett, Lenore M Scheel, Constance Miller for **Sophie H Marshall**; Kelly Hubbard for **Thomas D Russo, Sr.** Donald J Johnson for **Peggy Lewis Johnson**; Donna Payton for **Nancy Parker**.

**In Honor:** We also thank those who honored a friend or family with a generous donation to the APF. Elaine E Sasso for **Elizabeth Britton**; Sharon I Koch for **Jagger and Jake Liguori**; Masako Karonuma for **Terri Witter**; Anne Johnson for **Candace Johnson**.

### HOLIDAY GIVING

Joy comes from many different sources. We have joy when we share wonderful experiences with family and friends during the holiday season. We also experience joy as an outcome of giving - of ourselves and of our resources. What can YOU give to the porphyria community? One friend sent one of his paintings for the office, Nicole ran a race to fund physician education, and Jared made a video series to help people understand EPP. The APF welcomes all your resources and we look forward to hearing from you.

**CONTACT THE APF TO GIVE AS YOU WILL! 1-866-APF-3635**



*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](http://www.porphyrifoundation.com)**

**Is Your Membership and Contact Info Up to Date?** The APF is able to maintain our physician and patient education programs and many other services because of your support. Since we do not receive government funding, we need your support and donations. We also need your new contact information if you have a new address or email. Be sure to send us your email address so you can receive the ENEWS.

***Protect the Future*** program to train future experts is important. Please consider making a donation to this program. Yours and your children's future health depends on each of us supporting the training of doctors who will know how to treat us and perform research when our present experts retire.

**DON'T FORGET TO DONATE. YOUR HELP IS NEEDED TO EDUCATE PHYSICIANS AND PATIENTS AND SUPPORT RESEARCH-THE KEY TO YOUR CURE!!!**

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Permit No. 7279

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