

**RESEARCH VOLUNTEERS** Volunteering for research is the most important action you can take to change your future health because **Research is the Key to Your Cure**. Below are a few stories of APF members who volunteered as research patients. You, too, can be a Medical Hero and join Steve and Tracy and so many others who gave a day or more of their lives to help find important answers leading to new and improved treatments and a cure.



**Steve Stevens** writes, "I volunteered for the Alynham Natural History Study about a month ago, and yesterday (March 30) I went to Birmingham, Alabama to do the initial Observation Part of it. The APF set up everything to get me there and back home. Jessica at the APF office handled all the travel arrangements. I can't say enough of the awesome job she did. I didn't have any layovers longer than 45 minutes. That was amazing, because I have had layovers in the past last for hours. Thank You Jessica, for the great itinerary and asking for my input before you booked the flight. The plane tickets, food, taxi costs, etc, was covered by the APF, so the trip did not cost me a penny. I got to meet Dr. Bloomer and Dr. Singal. They explained to me what the study was and answered all my questions. I haven't met many doctors like them. After talking with them I could see and feel their sincerity about helping us. They are great. The study Administrator's name is Toni, and she is fantastic, too. She sat with me and explained the paperwork in detail and answered any questions I had pertaining to the study or questionnaires that I was answering. I was very impressed how professional and organized she is. She made sure everything was completed and I had enough time to get back to the airport in time for my trip home. She and the doctors/experts are very special people. I cannot say enough good about them. I am glad I volunteered for the study and would encourage anyone that has one of the acute porphyrias to do so also. I hope to volunteer for future research and hope others do, too. You are helping yourself, your family and future generations.

**Tracy Yelen** If you're at all interested in what they are doing to me in this Panhematin trial, I am happy to share.



During the entire stay, the medical team accessed my port. They drew all the blood they wanted without all the usual IV sticks, which is nice. Every morning after breakfast we did the infusions, which may or may not be a placebo. Neither the nurses nor I were allowed to see what was pumping into me. So I am blindfolded and there are sheets hung in the room to cover the medicine and tinfoil around the lines. It takes only a few hours to complete. I snoozed and chatted with the sweet nurse. Outside of that, the dextrose fluids are flowing in through my port 24/7. Otherwise, it was pretty uneventful. Why do I tell you this? Basically, I want to remind you of how important it is to volunteer as a research patient if you ever get the opportunity. There are lots of trials that even perfectly well people can do for various different studies and various different medical reasons.

**PATIENT EDUCATION MEETINGS from Desiree** To me, patient meetings are the best opportunity to learn about porphyria while enjoying yourself at the same time. What better way can a person be educated about their disease than to have one of the best porphyria experts in the world teaching you and then have the opportunity to ask questions about your own case. At every meeting, the expert who answers you is one of the ones who helped develop the treatment to save your life or improve your health. You also have the chance to meet other people with different types of porphyria. Over the past 34 years, I have seen many fast friendships develop at these meetings. Of course, it is such a wonderful chance for me to put a face to all the people with whom I have communicated for years or assisted in some way.



The most recent Oklahoma City meeting was held on April 11, 2015 and was outstanding. Porphyria expert, Dr. Sylvia Bottomley, made a superb presentation on each of the porphyrias and answered questions from the attendees. She also gave an in depth explanation of how each of the porphyrias are diagnosed and treated and all of the upcoming potential treatment. Several of our guests were also there to help and learn. Paul Stickler from Recordati Rare Diseases was available for questions related to Panhematin, and Dr. Amy Simon gave a presentation on the studies being conducted and to be conducted with the new Alynham Pharma treatment for acute porphyrias. EPP patient, Janie Kitchens gave an outstanding speech on the newest clothing, etc, for photosensitive porphyrias. AIP patient, Beverly Perry ended the meeting with one of her beautiful songs, *Almost Home*. To top off this wonderful day, Dr. Bottomley's husband, Dr. Richard Bottomley, gave the attendees a tour of the National Cowboy and Western Heritage Museum where the meeting was held. It was a thumbs up day!!!!

**NATIONAL PORPHYRIA AWARENESS WEEK** is the week that our members create their own awareness projects to heighten awareness in their communities. All across America porphyria people have used their time, talents and energy to heighten public awareness of the porphyrias. See a few below:



*Abby LeGrand*



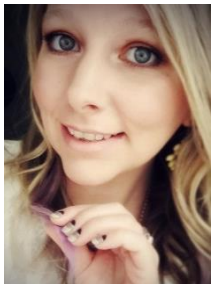
*Cook Brothers Hat Day*



*Shadow Ride*



*Levi & Megan Living in Light of Rare*



*Sarah dyes purple hair*



*Beverly Perry Sings*



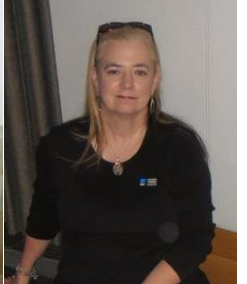
*Terri Witter brings nurse Jamie*



*Janie Kitchen and Keisha share*



*Elizabeth helps*



*Elizabeth helps*

**BIOCHEMICAL TESTING** it is important to locate a laboratory skilled in performing biochemical tests for Porphyria and a physician skilled in interpreting the test results. Porphyria can only be diagnosed with specific porphyria tests. The biochemical tests are urinary, stool and/or plasma porphyrins and porphyrin precursors (ALA and PBG) and/or enzyme assays depending on the type of porphyria. The APF can help you locate laboratories that can perform the diagnostic tests. However, the best lab for porphyria is the Porphyria Center and Laboratory at the University of Texas Medical Branch, headed by Dr. Karl Anderson. They can perform the biochemical tests needed to diagnose each of the porphyrias. To reach the UTMB Porphyria Laboratory, please contact the APF. To view their testing information and instructions, see <http://pmch.utmb.edu/clinics-services/porphyria-center>. Unlike most laboratories, Dr. Anderson is also available for consultation about your test results.

**FOR DNA TESTING** contact the Porphyria Center/Mount Sinai Genetic Testing Laboratory in New York City. They DNA test for **seven** porphyrias, including Acute intermittent Porphyria (AIP), Hereditary Coproporphyrinuria (HCP), Variegate Porphyria (VP), familial Porphyria Cutanea Tarda (f-PCT), Hepatoerythropoietic Porphyria (HEP), Erythropoietic Protoporphyrinuria (EPP) and Congenital Erythropoietic Porphyria (CEP). This is the only laboratory in the USA that offers DNA testing for all of these porphyrias. Before requesting DNA testing, it is recommended that patients have biochemical testing. However, many patients have not had an acute attack or are not symptomatic at present, so biochemical testing may be inconclusive.

In contrast, DNA testing is the most accurate and reliable method for determining if a person has a specific porphyria and is considered the "gold standard" for the diagnosis of genetic disorders. If a mutation (or change) in the DNA sequence is found in a specific Porphyria-causing gene, the diagnosis of that Porphyria is confirmed. DNA analysis will detect more than 97% of known disease-causing mutations. DNA testing can be performed whether the patient is symptomatic or not and requires only a small amount of blood sent to the laboratory at room temperature. Once a mutation has been identified, DNA analysis can then be performed on other family members to determine if they have inherited that Porphyria, thus allowing identification of individuals who can be counseled about appropriate management in order to avoid or minimize disease complications.

It is important for patients to realize the limitations of DNA testing. Each porphyria is caused by a mutation in the DNA sequence of a specific gene. Thus, the diagnosis of a specific porphyria determines what gene to test. Diagnosis of the specific porphyria can be difficult because the three acute porphyrias (AIP, HCP, VP) typically have similar acute symptoms, biochemical findings, and responses to treatment. This means, for example, that if a patient has been given the diagnosis of AIP and no AIP gene mutation is identified, it is possible that the patient has a different acute Porphyria. For patients with symptoms of an acute porphyria, but without a specific diagnosis, we offer a "triple test," which includes DNA testing for the three major acute porphyrias (AIP, HCP, and VP). DNA testing involves sophisticated DNA sequencing which is multi-procedural, labor intensive, and expensive. In the porphyrias, there are no common mutations so the entire gene must be sequenced in each new family.

## **DIAGNOSTIC TESTING for the Acute Porphyrrias- Clarification of Testing Results**

It has come to our attention that some patients who have been diagnosed clinically as having Acute Intermittent Porphyrria (AIP) or another acute hepatic porphyria could not be confirmed by either biochemical or DNA testing. Biochemical testing is the demonstration of increased urinary ALA and PBG, and these values are highest during an acute attack when patients are symptomatic. Some patients can have high levels in between attacks as well, but not all. Positive diagnostic values should be increased greater than 5 times normal, not just a slight increase (less than 3 times normal) which can occur with dehydration. Most commercial laboratories and in particular the Porphyria



Lab at the University of Texas Medical Branch in Galveston which is run by Dr. Karl Anderson, will perform these tests properly. It is important that the doctor order urinary ALA and PBG and not a "porphyrin profile."

DNA, or molecular genetic testing, for the acute porphyrias is performed by sequencing the causative gene for the three major acute porphyrias and finding a specific pathogenic lesion on the gene, called a mutation. The technique used for DNA testing is at least 98% accurate, and patients with significantly elevated PBG are most often found to have a specific mutation. In our experience of testing over 1,000 patients, with or without elevated urinary PBG, only a few cases did not have a specific mutation. For these patients, we undertake special testing to look for gene deletions or other aberrations that would be responsible for a cryptic mutation.

During the last few years, our experience with DNA testing for the acute hepatic porphyrias has revealed certain mutations which are not pathogenic but are relatively frequent in normal individuals who do not have any acute hepatic porphyric symptoms. These are called polymorphisms and they are benign. When we recognize patients who have such polymorphisms, we continue to look further at their DNA to see if we can find a pathogenic mutation in addition. If no pathogenic mutation is found, we would have to classify or reclassify these patients as not affected. As you may be aware this has created great concern for patients who respond well to acute porphyria treatment that their treatment would be discontinued. We appreciate this concern and would like to have such patients' physicians contact on us so that we can discuss their situation, recommend additional testing to determine if their symptoms may have been misdiagnosed and institute appropriate treatment.

**Diagnosing Acute Porphyria** The acute porphyrias include Acute Intermittent Porphyria (AIP), Hereditary Coproporphyrria (HCP), Variegate Porphyria (VP), and d-Aminolevulinic Acid Dehydratase Porphyria (ADP).

AIP is the most common of the acute porphyrias. The most common symptoms are acute attacks of severe abdominal pain, back pain, pain in the arms and legs, nausea, vomiting, rapid heartbeat and other symptoms. These attacks generally last for several days, and can be sporadic or happen frequently (~once/month). These acute attacks are very rare in children before puberty. These acute attacks are very rare in children before puberty. Attacks are often provoked by certain drugs, alcohol, hormones, infections, and perhaps stress. HCP and especially VP may cause blistering skin photosensitivity, as well as symptoms of acute attacks; AIP has no skin involvement, it is characterized just by these acute attacks.

### **A diagnosis of one of the acute porphyrias is made in two ways:**

#### **By biochemical testing:**

For AIP- a urine porphobilinogen (PBG) test during an acute attack—the urine PBG level will be very high if the symptoms are caused by an acute porphyria (greater than 5 times the normal value)

For HCP and VP- a urine porphobilinogen (PBG) test during an acute attack if the patient has acute symptoms, or plasma porphyrins if the patient has skin symptoms

#### **By genetic testing looking at the genes known to cause the acute porphyrias**

There are many misconceptions about the urine PBG testing, its reliability, and urine color of patients with acute porphyria. The urine sample for PBG testing needs to be protected from light; the sample should be wrapped in tin foil or placed in a brown opaque bag after collection. However, if the sample is exposed to light for a little while this will not affect the results. Please follow the directions provided by the laboratory when doing this testing. Urine PBG testing can be sent to many labs including Quest, LabCorp, Mayo, ARUP, UTMB and Mount Sinai; they all do this testing reliably.

Many patients have urine that is red/purple in color when they have an acute attack, but this is not always the case. Patients can still have elevated urine PBG levels even if their urine color is normal. These misconceptions may lead to improper testing, or misdiagnoses. Physicians who suspect a patient has an acute porphyria should call one of the expert Porphyria centers in the US to consult (<http://www.rarediseasesnetwork.org/porphyrias/index.htm>).

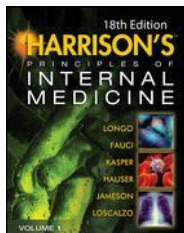
**The Difference between Active and Latent Acute Porphyria** It is important to know that ~80% of people who have changes in their porphyria genes (called mutations) never have symptoms of the acute porphyrias. These people are said to have "latent acute porphyria."

If someone has a mutation in an acute porphyria gene and reports symptoms similar to an acute attack, their urine PBG level should be checked. If the urine PBG level is normal then there is likely another cause to this person's symptoms. Acute attacks are distinguished from other conditions that cause abdominal pain by very high PBG levels.

**Treatment of Acute Porphyria** For patients with confirmed diagnoses during acute attacks, Panhematin® infusions are administered as treatment, and the pain is managed with various other medications. For more information on Panhematin® please visit: <http://www.aiporphyria.com/healthcare-professionals/treating-AIP/dosing>. If someone who does not have a confirmed diagnosis of acute porphyria, documented by very high PBG levels, is having symptoms that seem consistent with an acute porphyria attack, Panhematin® is administered at the discretion of the treating physician. Generally all other causes of abdominal pain which are much more common than acute porphyria are ruled-out first. If Panhematin® is administered and subsequently the diagnosis of acute porphyria cannot be confirmed by elevated urine PBG values or DNA testing, then it would be concluded that the "attack" is not caused by an acute porphyria. Even after Panhematin® treatment or after an acute attack has passed, the urine PBG levels should still be elevated for several days to a week. These levels may not be as high as they were during the acute attack, but will still be elevated. Below is a helpful table to understand the diagnostic process:

Type of Porphyria		Most Common Symptoms	Biochemical Lab Tests to Diagnose Condition	Labs to Use	Treatments
Acute Porphyrias	<b>Acute Intermittent Porphyria (AIP)</b>	Acute attacks of severe abdominal pain, nausea, vomiting, rapid heartbeat and other symptoms. These attacks generally last for several days, and can be sporadic or happen frequently (~once/month). Sometimes they can be triggered by certain medications. Generally symptoms start sporadic.	<ul style="list-style-type: none"> <li>Urine Porphobilinogen (PBG) done during an acute attack</li> </ul>	UTMB, ARUP, Mount Sinai**, Mayo, Quest, LabCorp	Panhematin infusions are given for acute attacks. Avoiding any known triggers of acute attacks; possible triggers can be found on the APF website.
	<b>Variegate Porphyria (VP)</b>	Can have the same acute attacks as in AIP, also can have blistering on sun exposed areas of the skin. Generally symptoms start in adulthood.	<ul style="list-style-type: none"> <li>Urine PBG done during an acute attack</li> <li>Urine total porphyrins</li> <li>Plasma porphyrins</li> </ul>	UTMB, ARUP, Mayo, Quest, LabCorp	Same as AIP for acute attacks, and avoiding sun exposure for blistering.
	<b>Hereditary Coproporphyria (HCP)</b>	Similar symptoms to VP.	<ul style="list-style-type: none"> <li>Urine PBG done during an acute attack</li> <li>Urine total porphyrins</li> <li>Plasma porphyrins</li> <li>porphyrins</li> </ul>	UTMB, ARUP, Mayo, Quest, LabCorp	
<b>Porphyria Cutanea Tarda (PCT)</b>		Blistering and skin fragility (skin that tears easily) on the sun exposed areas of the skin. Generally symptoms start in adulthood.	<ul style="list-style-type: none"> <li>Urine total porphyrins</li> <li>Plasma porphyrins</li> </ul>	UTMB, ARUP, Mayo, Quest, LabCorp	Avoiding sun exposure, and regular phlebotomies (removal of certain amounts of blood), or low doses of hydroxychloroquine (a medication).
<b>Erythropoietic Protoporphyria (EPP) and X-linked Protoporphyria (XLP)</b>		Severe pain on sun exposed areas of the skin, with swelling, lasting several days. Generally there is no blistering with the pain. Symptoms usually start in childhood.	<ul style="list-style-type: none"> <li>Erythrocyte protoporphyrin</li> <li>Plasma porphyrins</li> </ul>	UTMB, ARUP or Mayo	Avoiding sun exposure.
<b>Congenital Erythropoietic Porphyria (CEP)</b>		Severe blistering on sun exposed areas of the skin which can result in infections and scarring. Generally symptoms start in early childhood; in very severe cases symptoms can begin right at birth.	<ul style="list-style-type: none"> <li>Urine total porphyrins</li> <li>Plasma porphyrins</li> </ul>	UTMB, ARUP, Mayo, Quest, LabCorp	Avoiding sun exposure and treatment of infections if they occur.
<p><b>NOTE—To diagnose all of the porphyrias GENETIC TESTING is also recommended. Information on genetic testing can be found at: <a href="http://icahn.mssm.edu/departments-and-institutes/genomics/genetic-testing/test-catalog">http://icahn.mssm.edu/departments-and-institutes/genomics/genetic-testing/test-catalog</a></b></p> <p>**The Mount Sinai Lab only tests for urine PBG</p>					

**HARRISON'S Principles of Internal Medicine** is widely regarded as one of the most authoritative books on internal medicine and has been described as the "most recognized book in all of medicine. The most recent text includes an outstanding chapter entitled, **Porphyrias**, written by porphyria experts, Dr. Robert J. Desnick, and Dr. Manisha Balwani, who was one of our first APF Protect the Future doctors. Now Dr. Balwani is recognized among the esteemed experts in the country. Your support of the PTF program made it possible for Dr. Balwani and other PTF doctors to learn from the best experts in the world. Please continue to support this program for a healthy future.



### **THE PORPHYRIA RESEARCH CONSORTIUM of the Rare Disease Clinical Research Network of the NIH**

As a reminder, the Porphyria Research Consortium is a team of experts who are conducting the major life saving research for all of us. Dr. Montgomery Bissell, University of California, San Francisco; Dr. Karl Anderson, University of Texas Medical Branch; Dr. John Phillips, University of Utah; Dr. Herbert Bonkovsky, University of North Carolina; Dr. Joseph Bloomer, University of Alabama and Dr. Robert Desnick, Mount Sinai School of Medicine.



Desnick



Bloomer



Anderson



Phillips



Bonkovsky



Bissell

Research volunteers are needed for all types of porphyria, including a research project for a new Alynlam treatment for the acute porphyrias. It only takes one day out of your life, please call the APF office asap and become a Medical Hero. YOU are the KEY because RESEARCH IS THE KEY TO YOUR CURE. Call the APF 1.866 APF.3635

### **EMERGENCY ROOM GUIDELINES KEY POINTS**



The APF website has an Emergency Room Guidelines section on acute porphyrias designed for primary care and emergency room physicians. The following Key Points are essential for diagnosis and treatment:

1. The human porphyrias are clinical disorders reflecting defects in heme biosynthesis.
2. Acute porphyrias cause acute attacks of neurological symptoms that can be life-threatening.
3. Acute attacks are triggered by certain drugs, sex steroid hormones, reduced intake of calories and carbohydrate, alcohol and unknown factors.
4. Many of these factors stimulate heme synthesis in the liver, which in the face of a metabolic enzyme defect, leads to increased production of heme precursors that may be neurotoxic.
5. Delta-aminolevulinic acid (ALA) and porphobilinogen (PBG), are porphyrin precursors and intermediates in the heme biosynthetic pathway.
6. ALA and porphobilinogen (PBG) are almost always elevated in urine during an acute attack of porphyria.
7. The most common emergency room (ER) clinical presentation is acute abdominal pain. Other features may include seizures, confusion and hallucinations, and a progressive polyaxonal motor neuropathy, which can progress to paralysis and respiratory failure requiring a ventilator.
8. A high index of suspicion in the presence of nonspecific symptoms is important for diagnosis. A family history of porphyria, female sex, onset during the luteal phase of the menstrual cycle, or recent use of a porphyrinogenic drug may be diagnostic clues.
9. A new diagnosis of porphyria as the cause of acute symptoms must be substantiated by finding a substantial increase in urine porphobilinogen (PBG).
10. Treatment should start promptly after the diagnosis is made. Mild attacks are sometimes treated with glucose loading (e.g. 3L of 10% glucose daily by vein).
11. Most acute attacks should be treated with hemin (Panhematin®), Recordati Rare Diseases at: **www.recordatirarediseases.com or 866-654-0539**; 3-4mg/kg into a large peripheral vein or venous access port daily for 4 days. Reconstituting Panhematin® with human serum albumin rather than sterile water is recommended prior to infusion. This helps prevent phlebitis at the site of intravenous infusion.
12. Hospitalization is usually required for symptomatic treatment of pain, nausea and vomiting, correction of electrolyte imbalance and observation for respiratory impairment, either to a general medical service or ICU.

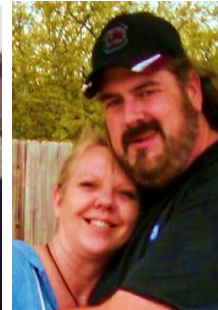
**OKLAHOMA FUNDRAISER** was held on April 11, 2015 was absolutely GREAT FUN! APF members, Tom and Mary Hull were the ultimate hosts of a fundraising event on their ranch near Pawhuska, OK. Their daughter, Dr. Lisa Kehrberg, has been instrumental in promoting porphyria education and awareness. Everyone who attended had a ball. The Hulls provided the Bar B Que, horseback rides, mule rides, and so much more. The ranch was beautiful. Mary calls it a "thin place," which are spots on earth that are so close to heaven that there is only a thin space between them. Her guests agreed. It was picturesque, complete with rolling lush green countryside and a creek that meandered across the fields. Mary and Tom's friends, Del and Tamara Garrison, Austin Voge, Robert Massy and Chaz brought their horse and let everyone ride, including greenhorns who had never been on a horse. Tina Avalone organized an auction and brought the beautiful flowers for the tables. It was a perfect setting for a perfect day. Some of the attendees had never met another person with porphyria. They all said it was terrific to be able to chat with another porphyria person and share experiences. Thanks Mary and Tom Hull for a day of happiness.



Layla epp



Amanda



Michelle and Scott



Del and Patrick



Andrew and Desiree



Del's boot and spurs



The Bar B Que with Dustin Pittsley Band



Megan, Lisa and Amanda



Dr Richard and Dr.Sylvia Bottomley



Mary Hull



Cowgirl Katherine Kehrberg

**NIGHT RUN** APF member, Shawn Willis, is hosting a FUN **Night Run** in Burlington, NC on Friday, June 19. The 5K race will begin at 8:30 PM and the 1K FUN RUN starts at 7:30 PM. The reason for the night run is that Shawn has EPP, a photosensitive porphyria. Shawn not only helps the APF, he supports and visits an orphanage in Africa and other charitable organizations. Shawn has EPP and participated in the Scenesse trials. Shawn owns several Chick-fil-As restaurants in Burlington, so be sure to go visit him when you are in town. Please contact the APF for details and Join the RUN.



**IN MEMORY** We send our sympathy to the family of Jennie Eberhardt, our first APF Presidential Award winner. She and her husband, Rich, were active helpful members for decades. Other friends and family also honored their loved ones with gifts to the APF. We join them in thanking you for your donations In Honor and In Memory: James D Purvis, Rebecca Perkins, Jo Anne Sorlie, Stephane and Shari Holland, Paul and Mary DeWitt, Phyllis Mistry for **Lisa Marie Grewal**; Thomas Zakrzewski, Desiree Lyon Howe, Beth Schomburg, Stephanie Phillips for **Krista Zakrzewski**; Janet R Murray, Joy D Talsma, Marilyn M DellOrto for **Norma K Winchester**; Mr. and Mrs. Jay Anthony, James and Karen Bousquet, Greg and Robbi Shanahan, James and Francesca Matthews, David and Mary Lee MacKay **for Doris M Bousquet**; Desiree, Rebecca A Wright, Richard A Eberhardt, Griffith and Patricia Schoonover, Jill Immenschuh, Francis R Thousand, Wisconsin Society of Land Surveyors, Alice Sprecher, Charles and Becky Wright, Ken and Mary Buzzell for **Jennie Lynn Eberhardt**; Karen Lavender for **Richard Lavender**; Elaine Smuczynski for **Helen, Jim and Joan**; Rosalie Nielsen and Lisa Kancsar for **Earl Trigger**; Rosalie F Nielsen and Lisa Kancsar for **Eugene R Nielsen**; Andrea F Wahlstrom for **Clarence Sather and Steven Sather**; Nueces Canyon Church of Christ, Muse, Stancil and Co for **Bradford Stults**.



**IN HONOR** Jere and Pauline Wise for **Rachel E Wise**; Joanne and Richard Bower, Anne Johnson for **Candace Johnson**; Paula Hendrix for **Ralph Gray**; Edward O'Connell for **Dr. Peter V Tishler**.

**NEW SATELLITE PORPHYRIA CLINICS** Three new satellite clinics have been established to enhance patient access to porphyria experts. As part of the APF physician education program, our present board of experts is mentoring the next generation of porphyria experts to make sure their level of expertise is not lost. This training is imperative because our present experts are approaching retirement. In fact, most of the experts have retired and small number of experts remains. To assure you of a healthy future, the experts joined the APF in establishing the Protect the Future (PTF) program. Yet they are working hard to assure you of a healthy future.



**Angelika Erwin, MD, PhD**, is a medical genetics physician in Cleveland, Ohio and is affiliated with the Cleveland Clinic. She received her medical degree from Charité-Jumboldt Univeristy Medical School, Berlin and her Doctorate at Eberhard-Karls Universität, Tübingen, Germany. After her Residency at Mount Sinai School of Medicine in New York, she became one of the Protect the Future doctors at the Mount Sinai Pophryia Center. Dr. Erwin has had an 11 year specialty in Genetic diseases, including treating porphyria patients. She is one of eight doctors at the Cleveland Clinic who specialize in Medical Genetics.



**Siobán Keel, MD** is a hematology specialist and an assistant professor of medicine in the Division of Hematology at the University of Washington School of Medicine in Seattle. Her expertise is in benign red blood cell disorders, iron metabolism, etc, and has now added neurovascular porphyrias. Dr. Keels graduated at Carleton College, Northfield, MN 1994 and continued her medical education at the University of Minnesota Medical School, Minneapolis, MN, her Residency: University of Minnesota Internal Medicine, and her Fellowship: University of Washington Hematology. Dr. Keel has been very active treating porphyria patients and has now become a PTF physician.



**Cynthia Levy, MD**, is a hematologist at Jackson Memorial Hospital, University Miami Sylvester Comprehensive Cancer Center and University Of Miami Hospital. She graduated from the University of Fed De Rio De Janeiro, Fac De Med, Rio De Janeiro, Brazil and now is the Fellowship Director of the Division of Hepatology at the University of Miami. We welcome her as a member of the PTF team. Dr. Levy has been serving the porphyria community near Miami, which previously was void of porphyria expertise.

We thank our new PTF doctors and are grateful to them for heading these new satellite clinics.

**INTERNATIONAL PORPHYRIA CONFERENCE** It is that time again. Every two years, porphyria experts and other medical professionals gather for The Congress for Porphyrins and Porphyrias. The next Congress will be held in Düsseldorf, Germany, September 14-17, 2015. This Congress is important to the future health of every porphyria patients as this is where the experts worldwide meet to share their expertise and updated research. Watch E-News for dates and agenda.



**AND PATIENT DAY at the International Porphyria Conference in Düsseldorf, Germany** We are happy to announce the next International Porphyria Patient Day will be during the Porphyrins and Porphyrias conference in Düsseldorf, Germany, to be held in 2015. The conference will take place from September 14th to September 17th, and the Patient Day will be on Sunday, September 13th. There will be many interesting presentations focusing on new emerging therapies, as well as the activities and support services of each of the organizations. Meeting people with porphyria from countries around the world is a marvelous experience. We hope as many of you as possible can join this gathering. Watch E-news for details closer to the date.

**BENT RODS BASS CLUB** Thanks to APF member, Victor Mejias, his fishing club, The Bent Rods Bass Club will be raising funds for the American Porphyria Foundation. The Club strongly believes in giving back and helping others.



Each year they select a charity to benefit. In 2014 they supported the Andrea Lynn Cancer Fund. To raise funds, they hosted a Frog only tournament (Frogapoolza) with all entry fees going to ALCF and they also raffled off a custom built drop shot rod, giving all ticket sales to ALCF.

This year they have selected the American Porphyria Foundation to be the benefactor of their funds. To raise funds, the club will be hosting a kiddie pole only tournament and raffling off a custom built bait casting rod. We wish the participants great success and lots of fun and thank them all for their generosity and interest in the porphyrias. Please contact the APF if you would like to join in the events and all the fun. The Tournament will be held at Deep Lake, Lakeview, Illinois on July 26, 2015. From sunrise to noon.