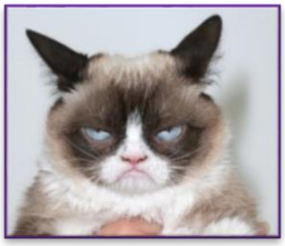
NATIONAL PORPHYRIA AWARENESS WEEK

April 16-23, 2016 is the time of the year that each of YOU has the opportunity to reach out and advance porphyria awareness in your local and medical communities. YOU are key to spreading word about porphyria. There are countless ways to accomplish this important task. The Cook family engaged their whole community in Vernon, TX by hosting a Barrel Race and Hat Day in their sons' school. Amanda Boston placed porphyria brochures in local doctors offices and taught her nurses and doctors about pophyria with every hospitalization. She also made a great video describing her type of porphyria. Shawn Willis and his family hosted a Midnight Run in Burlington, NC, and Victor Mejias hosted a fishing tournament for the APF. Claire and Bob Sadowniczak helped man the APF booth at the Hematology Convention, Lisa McFarland created a webpage for people to post their photos for the FDA, Colin McEwen shared his story on the APF website, Louise Schlosser will be hosting a patient support meeting, Amy Rose Burke serves as a Facebook administrator, and Andrew Turell serves on the APF Board. Almost everyone tries to educate their physicians and nurses. Some people have gone as far as speaking on local television and radio. Every effort to enhance awareness is important. The APF will assist you by providing educational brochures etc., for your activity. Below are some excellent outreach methods:

- Tell your story to the local television, radio or newspaper
- Share your knowledge with doctors or at your hospital seminars
- Set up exhibit booths at local health fairs or medical meetings
- Assist the APF at national medical conventions
- Volunteer your talents to help enhance patient and physician educational projects
- Host a community race or carwash to benefit patient and physician education
- Volunteer your skills, like computer skills, or business acumen to help the APF advance awareness and education
- Host a Fun Run or Walk-A-Thon or even a Night Run or Twilight Walk
- And many other means to make Porphyria known

Please let us know about your awareness event, so we can share your undertaking in the next newsletter.

PET BEAUTY CONTEST



Back by popular demand – The APF is hosting the **2nd Pet Beauty Contest**. Last time, there were all sorts of pets, including a PET ROCK. We can have FUN while FUNdraising to enhance Porphyria Awareness and Physician Education.

Entering the competition is FREE. All you need to do is mail or email your pet's name and photograph to the APF. All pets are welcome: pigs, dogs, cats, hamsters, snakes, goats, cows, etc., because all pets are beautiful!!!

Your pet's photo will be posted on the APF website for all to see. There will be two catagories of winners:

1. The pet who receives the greatest number of votes;
2. The pet who has the most people vote/donate for them.

Once your pet's photo is on the website, ask friends to vote for your pet with a $1 donation per vote and return the votes to the APF by April 16, the beginning of the National Porphyria Awareness Week. You can collect your pet's votes individually or together and send to the APF. **LET THE FUN BEGIN!!!!**

MEDICAL CONVENTIONS take place around the country on the state and national level. The APF maintains an exhibit booth at the conventions that are most important for porphyria, namely, American Society of Hematology (ASH) and the American Association for the Study of Liver Diseases (AASLD) and intermittent meetings like American Academy of Dermatology and Digestive Disease Week. Over 8,000 physicians attend each of these conventions, so our appearance there is a great educational opportunity to advance porphyria education.

We want to thank Amy Chapman and others for setting up the exhibit booth and overseeing the ASH convention and Claire and Bob Sadowniczak for assisting at the booth by distributing educational materials to physicians. You, too, can volunteer at the next convention and share your story with the physicians who stop by the booth for information. The APF will let you know when the conventions are scheduled in time to volunteer and participate. Distributing porphyria brochures to doctors is a very important endeavor. If a convention is in your area, please volunteer and learn, too.

no pain no gain

The old adage, ***No Pain, No Gain***, may work well in certain instances, but for porphyria, ***No Pain, No Gain*** is a terrible maxim. Most patients agree that porphyrias do not fit within the mainstream of painful conditions, like broken bones, labor pains, muscle spasms, etc. Porphyria pain is so severe that it is difficult to explain, but the people below have used their own extraordinary descriptions. After you read their quotes, you will understand why porphyria has gained a reputation as one of the most painful diseases.

Travis Moore created the photo on the left to prove a picture is worth a thousand words.
Victor Mejias (EPP) It itches and burns so bad it makes me climb the walls.
Emily Melone (AIP) It is like "charlie horses" in my intestines.
Mike Boone (AIP) I want to unzip my skin and step out. My ribs feel like they are being fileted.
Karen Eubanks (AIP) I am being kicked with a steel toed boot.
Kim Stala (EPP) My hands feet and face are in boiling water for days while a knife is cutting and twisting my insides.
Monique Jacobs (HCP) My skin is akin to jellyfish stings while my belly burns like a washing machine full of lava.
Steve Stevens (AIP) My rib cage feels like the lava inside a volcano with lightning bolts going off.
Tara Cantley (AIP) My arm feels like someone cut off the circulation with a tie.
Lisa McFarland (EPP) It's like sticking your hands in a vat of hot frying oil with no relief in sight.
Stacy Hermann (AIP) I feel confused, angry, and full of deep despair. I cry at nothing at all.
Rachel Shinn Olstad (HCP) My daughter says it is like a knife stabbing her thigh over and over.
Debbie Rohn (AIP) My daughter says it's like getting stung by thousands of bees and peroxide in her veins.
Deb Miller Gilbert (VP) My nerve endings are firing all at once and I do not get a break from it. My nerves are so overstimulated that a loving hug from my son is excruciating.
Tara Cantley (AIP) Someone is squeezing my arms and legs until they go numb and nerves feel as if they're burning.
Theresa Flagg Jurls (PCT) An inflated object with steel spikes caught behind my right ribcage.
Rachel Johnson Keith (AIP) Demons are chewing their way out of my gut and standing in a pile of fire ants.
Nicole Marie DiRoma (AIP) Severe burning torch in my stomach, being pregnant for your whole life and muscle pain like a 500lb person sitting on you and won't get off.
Rachel Ballew Campbell (AIP) It feels like someone is slicing your insides with a straight razor, while pouring hot lava through them. There really is no way to explain it.
Beverly Tuberville (AIP) Fire ants are all over.
Jennifer Taylor Nay (AIP) It feels like I am digesting glass shards.
Gregary Scott Allen Edwards (AIP) It's like being run over by a steam roller, shot by tasers repeatedly, and having all my life force batteries drained instantly.
Terri Witter (AIP) I have a tummy full of broken glass.
Mary Schloetter (AIP) My bones feel like rolling in glass shards and acid moving through my veins. Episodes are called 'attacks,' I agree as I'm standing alone on a battlefield being hit with guns, cannons and tasers.
Christine R. Baer (AIP) I have a knife through the abdomen, and my insides have jitters and dancing and moving.
Lisa Coleman-Vinson (AIP) It's like digesting huge, hot rocks with bone crushing pain.
Theresa Flagg Jurls (PCT) Steel spikes poking into my abdomen and ribcage, steel clamp gripped to pelvis.
Beth Nye (AIP) A 600lb person is sitting on my stomach and twisting it like a wet towel to remove all the water.
Nicki Theisen Maus (AIP) My insides feel like they're on fire!
Rogers Reyna (AIP) It's like aliens use my back as a trampoline while chewing their way through my gut. The nerve pain burn is fire ants having a festival in my arms and legs!
Patty Harris (AIP) Firing swords of hell with demons eating their way through your stomach back, legs, arms, and head. Let's face it, porphyria is burning hell.
Joe Mrsny (PCT) I look like I have leprosy because of the blisters breaking open. The itching is unbearable and causes scars and it usually comes at night so I am sleep deprived. The sun hurts. My finger nails fall off so I am unable to button my clothes. I just want to lay down and stay out of sight.

Whitney McCabe Stevens (HCP) Reality is, I can't accurately describe the pain of an attack because it is the most horrendous and overwhelming pain I have ever felt! On the pain scale of 1-10, it's 10,000. In my opinion, words simply can't accurately describe what we endure.

There is HOPE

Blue Therapeutics is a Harvard start-up founded by Ajay Yekkirala, Michio Painter and David Roberson, which is creating a new kind of painkiller that may be proven to be more effective than existing opioids and may eliminate the risks for addiction: http://nationalpainreport.com/start-up-creating-non-addictive-painkiller-more-powerful-than-morphine-8829101.html

At the invitation of Dr. Jonathan Goldsmith (photo top), FDA Associate Director Rare Diseases, and Ms. Laurie Haugley (photo mid), FDA Professional Affairs & Stakeholder Engagement Associate for Assistance, the APF Ex Director, Desiree Lyon Howe, porphyria expert, Dr. Robert Desnick and AIP patient, Ms. Ariel Lager (photo bottom), will attend a meeting on March 7, 2016 to provide up-to-date information about the acute porphyrias, including the genetics, epidemiology, pathophysiology, natural history, current management and emerging therapies. This meeting will also provide Ariel Lager with the opportunity to help them gain insight on the patient perspective of the acute porphyrias.

The focus of the meeting is in preparation for a half-day gathering to be held later in the year. During the large meeting, acute porphyria patients and experts will be invited to share their experiences and insights on the following topics: disease symptoms, daily life impact of porphyria, current treatment approaches and therapies in development worldwide. These *Patient Voice Meetings* will provide acute porphyria patients ages 18-65 with the opportunity to present their experiences and will include patients with infrequent, sporadic attacks and the most severe recurrent attacks, as well as those who experience chronic symptoms, patients who are using heme products on demand for acute attack treatment and patients who are using heme prophylactically to prevent attacks. We will update you on the meeting planning via the Enews.

If you would like to attend the *Patient Voice Meeting* and make a presentation at the FDA on your type of porphyria, please contact Desiree at the APF. This is an exciting opportunity for patients to play a major role in the FDA understanding of current and emerging treatments.

THE 21ST CENTURY CURES ACT AND YOU

The *21st Century Cures Act* is important to you because the ultimate goal of this act is to close the gaps between advances in scientific knowledge about cures and the regulatory policies created to save more lives. Key aspects of the bill, which the Senate is not expected to vote on until later in 2016, include steps to streamline clinical trials; advance personalized medicine by encouraging greater use of drug development tools, such as biomarkers; and creating incentives for developing drugs for uncommon but deadly diseases.

It accepts alternatives to multiphase clinical trials in certain circumstances, and permits accelerated approval pathways for certain classes of drugs. Under the new criteria, the agency may consider not only randomized clinical trial data, but also, observational studies, registries and therapeutic use as evidence of efficacy for drug and device approvals. Read more at: http://energycommerce.house.gov/cures#sthash.pswvsBzI.dpuf

THOSE WHO KNOW THE MOST-DO THE BEST

Patient Education Meetings are a valuable source of education and camaraderie. When a person has a rare disease there may not be another patient within 100 or 1,000 miles. That is why attending a patient meeting is helpful to everyone. Although it is great to share information about porphyria among patients, it is essential that you have the facts about your disease, preferably from a porphyria expert. Recently, the APF hosted a patient meeting in Orlando, Florida in conjunction with the American Society of Hematology (ASH) Convention. APF member, Amy Chapman, led the meeting, and Dr. John Phillips, a porphyria and heme expert from the University of Utah, made a presentation and answered questions from the attendees.

If you receive this newsletter in time, the next patient meeting will be held in Houston, TX on March 14, 2016. Please feel free to come and bring your family and friends. If you are interested in hosting a meeting at your home, church, club, or any venue, the APF will provide you with educational materials and in most cases, a doctor to make a presentation. There is always time to view the APF DVD *Porphyria Live* and talk with other people who have porphyria. If you want to attend or host a meeting, contact the APF. **Below are a few sites and suggestions that also will increase your knowledge of the Porphyrias:**

The Heme Pathway is explained in this website as is how each porphyria occurs. See: *Heme Pathway made Simple in Porphyria:* https://www.youtube.com/watch?v=970btK0G3-0

For Diagnosis, only a few laboratories in the country can perform the biochemical tests.

See these labs on the APF website at: http://www.porphyriafoundation.com/testing-and-treatment/testing-for-porphyria/us-porphyria-labs *Please note that EPP ONLY should not be tested at Quest or Labcorp.

See DNA Laboratory at: http://www.porphyriafoundation.com/testing-and-treatment/testing-for-porphyria/dna-testing-for-porphyria

See International Laboratories at: http://www.porphyriafoundation.com/testing-and-treatment/testing-for-porphyria/international-porphyria-labs

LIVER TRANSPLANT FOR AIP As told by Kim Burrows Stockdale. *I have no idea why the porphyria attacks began in my forties. My daughter had mononucleosis and was in the hospital. I got ill shortly thereafter and thought I caught it from her. But when serious symptoms continued, the doctor sent me to hospital where I remained for six months. I had pain and seizures which didn't stop with medication. I wondered if it was connected to my mother's death from liver and kidney failure. Thus, I went from never having a porphyria attack five years ago to this sudden attack prone lifestyle of D10 every day 12 hours a day and Panhematin for 7 days a month.*

It started with diarrhea. I could not keep food down and began losing weight. After checking my abdomen and digestive system, doctors found nothing wrong. I was losing weight so fast that I became malnourished. Finally, I was tested for porphyria and was diagnosed with AIP. They started Panhematin treatments and D10 at home. But that did not keep me out of the hospital, and I had to have ten ports installed. Even when I went to the clinic twice a week, I still had never ending attacks. My hospitalizations were so frequent I was in more than I was out of the hospital and very ill all the time. My doctors began discussing a liver transplant. Anything sounded better than life in the hospital so I agreed. After consulting with Porphyria expert, Dr. Angelika Erwin, who is one of the APF Protect the Future doctors, I felt I needed to go ahead with the transplant if I ever wanted a normal life again. In fact, I was worried I would not live at all because my skin was yellow and I was jaundiced and in serious pain.

I received word that Cleveland Clinic had a liver for me and that I would have the surgery tomorrow. A group of nine doctors arrived shortly thereafter, including the transplant surgeon. They told me the surgery would be 12 hours and that I would be in ICU for five days and on life support for three days. So on July 1, 2015 at 9 PM, the transplant began. After the transplant, I was up and about by the end of August. I wore a mask for protection but was otherwise fairly normal. I expected to be much worse but discovered it was surprisingly easy compared to my imagination. I am attack free and am glad I had the transplant. It is not for everyone but for me it was great.

SELF DIAGNOSIS: THE GOOD AND BAD Although the internet is an excellent means to find out information, self-diagnosis can be dangerous. For example, recently, people unknowingly were turning to websites, like *23andMe* and *LiveWello* to find out if they had porphyria. Since many of the reports had genetic information that seemed similar to porphyria, people diagnosed themselves with the disease. Thus, the APF contacted renowned geneticist and porphyria expert, Dr. Robert Desnick, to help clarify these tests. He kindly responded,

It has come to our attention that some Porphyria patients have sent their DNA to 23andMe or to other commercial companies, and have gotten results suggesting that they have "DNA confirmed Porphyria". We are concerned that results from companies other than DNA testing laboratories that have experience in diagnosing porphyrias may provide patients with misleading information.

A major issue with DNA testing is whether a gene alteration (variant or mutation) is pathogenic (disease-causing) or benign (a change in the gene that does not cause or make one at-risk for the disease). For example, 23andMe does NOT do gene sequencing, but does determine if you have various gene alterations in the porphyria genes, all 57 of which are benign, and are not disease-causing but occur in a particular gene in which other lesions are in fact disease-causing. The benign lesions usually are identified by an "#rs" number. These benign changes are quite common but may lead a patient to believe that he/she has one or more porphyrias. They do not affect the heme biosynthetic enzymes, as they are not pathologic lesions. Of the gene lesions that cause disease, over 98% would be identified by gene sequencing as is done for all the Porphyrias at the Mount Sinai Laboratory and four Porphyrias at the Mayo Laboratory.

The Mount Sinai Genetic Testing Laboratory provides Porphyria DNA testing for all eight Porphyrias, and has a full-time Porphyria Genetic Counselor, Dana Doheny, MS, who is available to assist in arranging testing and interpreting the results. Typical time from receipt of sample to result is about two weeks. If the patient has "biochemical-positive" results and a DNA alteration cannot be found, there is a 1-2% chance that the patient has a "cryptic" mutation or a large deletion in the porphyria gene that is difficult to find by sequencing. The Mount Sinai Laboratory will do additional analyses to find the Porphyria gene lesion, if the patient has one.

After receiving the letter from Dr. Desnick, we also received a very lengthy letter from *23andMe* and *LiveWello*, explaining that it is IMPOSSIBLE to diagnose porphyria with the information that they provide. They, too, stated that there was not enough data to diagnose porphyria and most other diseases. If you have questions or need a diagnosis, please call the APF at 866.APF.3635, and we will assist you in getting a diagnosis.

A BIG THANK YOU The APF owes a big THANK YOU to Caul and Cason Cook's family of Vernon, Texas for hosting the *Shadow Race-Barrel Race*. We also thank Shawn Willis and his family for hosting the *Midnight Run* in Burlington, North Carolina. These two families raised $4,500 dollars for the APF Physician Education Program.

Colin McEwen *In my late 20s, I began my career in non-profit communications and met my wife. During our engagement, I had a mysterious abdominal illness that began with mononucleosis and abdominal adhesions. I continued to have frequent episodes and my first seizure in ten years all of which was attributed to a prior car accident. During my desperate search for relief, a quack implanted a device so wrong that even the insurance company denied the $35,000 medical tab.*

My quest for a proper diagnosis and treatment led to taking pain medication and not eating well. I developed severe anxiety, insomnia, severe confusion, etc., which my family believed was due to prescription drug abuse. I was sent to a detox and rehabilitation facility where the severe back and hand pain and tremors began. Doctors incorrectly treated me for delayed withdrawal syndrome. Out of desperation, I self-medicated with alcohol, because I dared not use pain medicine again. Soon the tremors turned to weakness and weakness turned to complete paralysis in my hands and arms and leg weakness.

After endless tests, a neuromuscular specialist said I had chronic inflammatory demyelinating polyneuropathy (CIDP) and treated me with IVIG. I regained strength and mobility, so we thought I had a correct diagnosis. A few months later, I suffered a CIDP relapse. After the relapse, my employer terminated me due to my disability. Out of sheer boredom, I built a coffee table. People wanted other furniture, so I set up my own shop called dEAD HANDS: Function and Form Furnishings, as a tribute to the permanent paralysis in my wrists and thumbs. Everything seemed to be going in a completely new direction. Until the summer of 2015, it all happened again. Abdominal and back pain, tremors, severe mental distress, paralysis in my arms and legs, frequent falls, tachycardia, etc. Needless to say I was hospitalized. This time, the IVIG wasn't working, so I was put on Klonopin to relieve the anxiety and hypertension. Things only got worse. After two weeks, I awoke completely paralyzed and was sent to the inpatient physical rehab center for three weeks where I made a mild recovery and was sent home in the care of my wife.

My recovery was extremely slow and my poor wife could not provide the 24 hour care I needed. The doctors became less certain of my diagnosis and prognosis and got me an appointment at the Mayo Clinic. They conducted an exhausted list of tests and exams and left no orifice unturned. Of all the state of the art testing that they performed, the one test that provided me a diagnosis was a simple urine test and DNA. I had AIP. I am a ***Porphie****.*

I am happy to report now that I am back in the shop building furniture. The doctors have made the necessary changes to my medication. I am eating a lot more carbs, like ice cream, and getting my rest and am managing AIP. It is an opponent I look forward to defeating. This has been a tough 18 years since my first seizure, but I have an incredible wife I love more than anything on earth, and I have a long life ahead to spend with her. What else do I need? Editor's Note: Colin suggests putting a "thank you" notice to the EMT on your MedicAlert bracelets.

PERSON IN PAIN-NOT ADDICT This is a very important subject for people with porphyria who are on prescribed pain medications, including opioids, for extreme pain. Approximately 100 million Americans suffer from chronic pain. Although chronic pain is a common experience, most people in pain suffer in isolation and are misunderstood by their doctors, co-workers, families and friends. Many go untreated or under-treated and are often incorrectly tagged as "drug seekers."

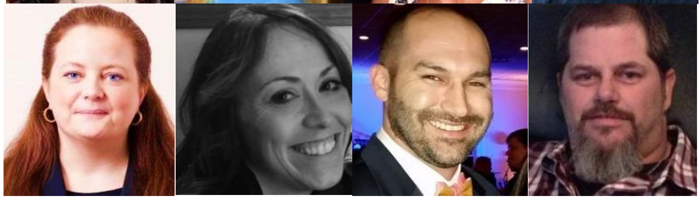
In a recent *Google* search of the word "opioids," 50% of the search results were targeted on addiction and abuse, and only 4% of the results dealt with the proper use of opioid pain medication. Much of this attitude has developed because of how opioids and other strong pain medications have been covered by the media. Most of the time, people taking opioids are portrayed as drug addicts, rather than people who are in very severe pain and need opioids to help them live as normal a life as possible. In the case of the acute porphyrias, narcotics are used because of drug safety issues.

Recently, new very restrictive drug guidelines were attempted to be initiated throughout the country. If it were not for a surge of people who live in chronic pain objecting vehemently to the new proposed pain guidelines, these new guidelines would already be a fact of life for all United States citizens. This is why we must continue to stay informed on unfair proposals.

People in pain are ordinary people, like you, your loved ones, friends, neighbors and co-workers. Each one desires to recapture just a small piece of the life they enjoyed before their never-ending cycle of pain began. The APF is enlightening you on our Pain Program to promote porphyria as a condition that should receive appropriate pain medications throughout the country. Some states maintain a list of diseases that are noted for chronic and extreme pain. State legislators work with their state health departments to prepare these lists of diseases. You can help by sending your pain experience to the APF. Please include a photo of yourself and your type of porphyria.

RESEARCH IS THE KEY TO YOUR CURE: JOIN AS A RESEARCH VOLUNTEER AND BECOME A MEDICAL HERO

NEW COMMITTEES The APF has created two important new committees to help improve the services of the APF. These committees are comprised of our members who donate their time and talent. Your **EPP FDA Advocacy Committee** has been ongoing for three months and has already done an outstanding job of promoting accelerated approval of Afamelanotide, the revolutionary treatment for EPP. They collected 300 letters from EPP families and friends, mounted a letter and email campaign to Congressmen and collected photos of EPP reactions to send to the FDA. Undaunted, they are continuing their charge. Committee members are shown below (l to r on row 1 & 2). Row 1: Lisa McFarland, Kristen Wheeden, Gayle von Seggern, Andrew Turell, Rob Saupe, George Hodder, Shawn Willis, Dave Garrett, Mike Kenworthy Row 2: Martha Petersen, Rebecca Griffiths, Pierre Mouledoux, Victor Mejias.



The APF has two additional committees that will begin in April, namely, the Legislation Committee and the Media Committee. Contact Desiree at lyonapf@aol.com if you are interested in participating.

The Patient Advisory Committee has a different role. They meet by conference call with Desiree, Executive Director of the APF, to discuss member needs, problems, future programs and services and committee suggestions to improve the APF. The committee represents members with each type of porphyria. However, we need a CEP member if you want to join. The 2015 committee members are (l to r): Desiree Lyon Howe (AIP), Diana Ijames (EPP), Joe Cochrane (PCT), Benjamin Stratz (VP), Ruth Bruno (AIP), Mary Schloetter (AIP), Elizabeth Petersen (AIP), Michael Boone (AIP), Joe Mrsny (PCT), and Jeannie Smith (HCP).

PORPHYRIA CONSORTIUM MEETING will be held in Houston March 13-14, 2016. The Porphyria Consortium (PC) is a group of porphria experts/researchers and their research teams. Many of you are already playing a major role in research as patient research volunteers, so you know the research coordinators and scientists. These scientists are responsible for the major research that has transpired for the last three decades.

The PC includes six of the leading porphyria centers in the United States that provide expertise and experience in the diagnosis and treatment of patients with porphyria. The staff in each center includes porphyria physicians, researchers, research coordinators, and technical/laboratory staff. Together with the American Porphyria Foundation, the Porphyrias Consortium enables a large scale collaborative effort to develop new strategies and methods for diagnosis, treatment, prevention of illness and disability resulting from these rare disorders.

Of particular importance is the Longitudinal Study, which has the objective of characterizing the long term course and outcomes of each porphyria. Clinical trials are being conducted to establish the safety and efficacy of new therapies leading to approval by the US Food and Drug Administration. Support for the Porphyrias Consortium is provided by a grant from the National Institutes of Health as part of the Rare Disease Clinical Research Network.

Another important role of the PC is to train future experts in our *PROTECT THE FUTURE* program. By mentoring these brilliant young physicians and scientists, the PC will share their expertise gained over the last thirty years and none will be lost. You will be interested to know that the PTF doctors also attend the PC meetings, participate in research, diagnose and treat patients and will be treating your family when the present experts retire.

CALIFORNIA SUPPORT MEETING

hosted by **Louise Schlosser**, Kick-Off Porphyria Awareness Week
Hear a presentation on porphyria, current and emerging treatments and share your experiences
Bring Family and Friends! April 16, 2016 11AM PST
RSVP: 714.686.6338 or Email: louise23rdpsalm@gmail.com
1925 Young Drive, Placentia, California 92870

READ THE INSTRUCTIONS: ***AMBER MARRS*** says, *I went to the ER as I was in bad need of Panhematin to stop my AIP attack. My surgeon was on vacation, so I didn't have my port installed yet. The ER staff tried repeatedly to start an IV and finally got a very small needle into a small vein. I told the doctor that Panhematin should go in a large vein, but he said, "Do you want the Panhematin or just pain medications." He said it like I was just drug seeking. I told him I wanted the Panhematin but only if it was given correctly. Also, yes, I needed pain meds since I had been in an attack for four days and was in severe pain. The doctor wouldn't listen to me. When he began infusing the Panhematin, it instantly started burning badly. When I objected, he said I was the patient and to stay in my lane.*

Editor's note: The photo shows what occurred, because no one read the instructions on correct infusion. Panhematin is a very effective drug but must be used as instructed. Experts also recommend using albumin with Panhematin in place of sterile water. We also encourage you to contact the APF to request a doctor packet, written by porphyria experts, be sent to your doctor.

DEB GILBERT "At first, I had a similar response with Panhematin, due to where and how it was infused. I was dying. I was BAD, BAD, BAD with no answers and no relief. *Then thankfully the Panhematin was infused correctly and Panhematin saved my life*. I also had what the doctors wanted to call a migraine that did NOT let up for 18 months!!! After my first treatment of Panhematin, there was a lessening of the migraine. Then after the second treatment, the headache was lifting, and a dim ray of light could be in my room. Prior to the treatment, I could not tolerate light. That night, I had my last convulsive episode. Panhematin stops the intractable, horrible pain of an attack. Nothing compares to getting your life back, even if the life you regained was only a portion of the life you were living. I am forever thankful for Panhematin. Now I have a port, and the rest is history. I get infusions usually 1-2 times a week. It was miraculous in treating me. Luckily for me!!!" (Photo left in hospital) If you have questions about treatment, contact the APF at porphyrus@porphyriafoundation.com or 866.APF.3635.

LEONA YOUNG, mother of the APF cofounder, James Young, passed away on February 5, 2016. Leona was a supporter from the beginning of the APF and also assisted us in our fledgling years. Her granddaughter, Tracy Yelen Nudo, who is an APF member, says, "My grandmother was the most beautiful and strong woman I have ever known." Leona instilled a great heritage of love, compassion and service for others; a tradition her family continues. Leona's funeral was at Trinity Evangelical Covenant Church in Oak Lawn, IL, on February 15th. We miss dear Leona Young and thank her for her years of service.

IN MEMORY AND HONOR Over the last 30 years, friends and family members have chosen to honor their loved ones with gifts to the American Porphyria Foundation. We sincerely thank you for your generosity and for remembering the person with porphyria and the APF.

In Memory We send our sympathy to the family and friends who honored their loved ones:
Jo Ann A Vollenweider, Gene Bartlett and Joan Stockoff, Thomas J Harris for **Daniel Pudlicki**; Elaine Smuczynski for the **Smuczynski clan**; Kathleen Toelkes, Linda Peterson and Valine Jensen for **Donna Pagano**; Grace Ann Feczko for **Robert S Zieles**; Michael P Farina for **Vincent K Farina**; Michael McAfee for **Laura Yandell**; Stephanie J Sadler for **Melinda Marcalo**; Paul Busse for **Vivienne Busse**; L Brad Moon for **Sharon Moon**; Norma Brown for **Matthew Brown**; Susan Nuckols for **Camden Nuckols**; Thomas R Walsh for **Jane I Walsh**; Mary P Crown for **Mary Hargett Crown**; Gary Horn for **Sandra Horn**; Donald J Johnson for **Peggy Lewis Johnson**; Charlotte E Wiedman for **Alice Ryback.** Desiree and Dick Howe, Lelia Brougher, the Porphyria Consortium, Drs. Karl Anderson, Robert Desnick, Herbert Bonkovsky, John Phillips, Joseph Bloomer, Montgomery Bissell, and What the Hale Music Production, Inc. for **Leona Young.**

In Honor We also thank those who donated in honor of a friend or family member:
Elaine Sasso for **Elizabeth Britton**; Sharon I Koch for **Debbie Koch**; Linda Nagin for **Melissa Nagin**; Angela Neal for **Lisa Neal**; Sharon P Dill for **Scott Dunbar, MD**; Judith Jimenez for **Julio Jimenez**; Gloria R Sheehan for **Paul Sheehan**; Karol D Webster for **Kim Bastian**; Sara and Douglas J Collier, Robert C Dubard, Mary Frances Donnelly, Myrna and Donald Cartledge, Robert E Hendrix, William A Gray, Paula M Hendrix, Kathleen A Shiel, Sera Elaine and Douglas Collier, Sarah and Lawrence Pritchard for **Ralph Gray**; Elizabeth H Petersen, Nancy and Mark Blum for **Desiree Lyon Howe**; Margaret E Whittenburg for **Jacelyn and Jamie Whittenburg**; Anne Johnson for **Candace Johnson**; Dale Moczynski for **Alicia Moczynski**; David Russell for **Craig and Nicole Leppert**; Jennifer McLellan for **Rene McLellan**; Suzy Godsted for **Matthew Godsted**; Adrienne Young for **Susie Young and Tracy Yelen Nudo**; Barb R Schaefer for **Trampus N Tribbey**; Carole F Gaudette for **Tristen Gaudette**; Marlene Brezee for **Jill Blake**.