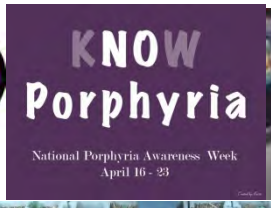
AMERICAN PORPHYRIA FOUNDATION

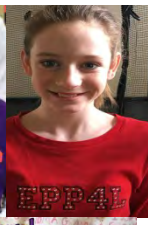
2nd Quarter, 2016

WOW, WHAT A WEEK!!!!!!!!!

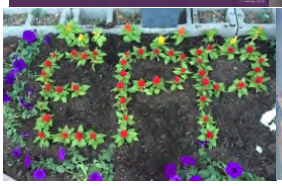
Porphyria Awareness Week this year was over the top. We had more participation than ever. People shared their stories and photos on all sorts of venues, including social media. They set up exhibit booths to distribute educational materials. Some wore "porphyria" clothes and pets wore APF bandanas. Cassie planted a garden spelling EPP. Yvette and Jessica wore their APF shirts to work and facilitated all the requests for materials. The response was so effective and heartwarming that everyone in the USA should know the word, porphyria. Enjoy the photos below:











RARE IMPACT AWARD

APF Executive Director, Desiree Lyon Howe, was one of the recipients of the 2016 Rare Impact Award from the National Organization of Rare Diseases (NORD), which represents 23 million Americans with rare diseases. Other recipients included, Arthur Caplan, Ph.D., Stephen Cederbaum, M.D., Senator Orrin Hatch (R-UT), and Representative Doris Matsui (D-CA). NORD hosted the event to bring together the rare disease community and to honor and celebrate outstanding achievements. They recognized the individuals, organizations, advocates and companies that are moving us forward in the fight against rare diseases.

We are grateful to Desiree for her 34 years of service to the APF and the rare disease community. She has spent her life making a positive impact on the rare disease community going above and beyond, overcoming many obstacles to help make a meaningful change in other's lives, promoting awareness of the porphyrias and advancing porphyria education and research. Desiree credits the APF Scientific Advisory Board with the APF's great success.

EPP/FDA ADVOCACY CAMPAIGN *pushing the limits!!!*

FDA Approve Scenesse (Afamelanotide 16 mg)

Do you remember the movie where the ending was a group of people yelling, "I'm mad as H---, and I'm not going to take it anymore!!!" Well that is what has happened with patients over the FDA still not approving Afamelanotide/Scenesse for EPP. EPP patients and their families are MAD, and they should be. It is outrageous for the drug to have been approved in Europe since October 2014; 1,000 implants have been given safely and Phase II and Phase III trials were completed years ago in the US. The APF and our members are putting pressure on the FDA. Once a week a big packet from the APF arrives on the desk of Dr. Kendall Marcus with photos, letters, emails, etc., to the committee she heads that reviews the Afamelanotide for approval. WE have received not one word from her. She has not even the decency to thank us for the 600 letters and photos that continue to arrive weekly. But we cannot let off pressure now. We know everyone is busy, but this is your chance for a normal life and writing a letter or sending a photo will only take you moments. Congress has mandated that the FDA have patient input and patient experience in both drug development and drug approval. This is not happening at the FDA. Please send more letters and more photos, write or call your Congressmen and ask your doctor to get involved. See the stack of 600 photos and letters from patients that we sent to the FDA commissioner. Patients can remain in the sun without suffering, play ball, walk to their car, go to the beach, climb mountains, travel, and work at the job they want. Your HELP is needed!! We will not stop until the FDA approves Afamelanotide/Scenesse. Ten patients visited the FDA years ago to advise the FDA about EPP. Yet when the FDA Dermatology Committee met, the Committee had NO information about our meeting and NO patient input on the drug. **CONTINUE TO PUT PRESSURE ON THE FDA**

PET BEAUTY CONTEST THANK YOU to everyone who entered the contest and donated on behalf of these beautiful pets. It was great fun, while raising funds for Physician Education! Pets bring joy, happiness and love to our lives and are a special medicine. Enjoy all the stories with the pet photos. Visit the APF website to view all the winners: http://www.porphyriafoundation.org/content/pet-beauty-contest-2016. The Winners are:

Most Votes and Most Voters: TIE - Callie Journey (Amy Simon) and Hazel (Judy Phelps)

Cutest Married Couple: Mrs. Silkie Sue and Mr. Fuzz Bucket (Ashley O'Neal Allen)

Cutest Feathered Friends: Kahnee and Gabriella (Pat Galvez)

Oldest APF Member: Alamo the turtle (Claire and Bob Sadowniczak)

Cutest Canines: Weenzie (Desiree and Dick Howe), Dr. Chico Loves, M.E. (Edwin Brandt), Jack (Joni Welda), Princess (Reyna Rogers), Delta (Barbara Lasater), Eben and Bentley (Mary Schloetter), Daisee Mae (LeeAnn Cook), Jacks (Jude Diner), Kenta (Yoshiko Williams), Oso (Heather Zamora), Harley (Kim and Perry Bastian), Yngwie (Donald Cox), Carson and Skye (Kim Fellows), King Louie (Marissa Morrissey), Cody and Sofia (Sherri Salazar), Zamboni (Jennifer Sutter), Dexter (Megan Dawson), Bella (Sue Fabian), and Lucy (Darlin Gwin)

Fabulous Felines: Sparkles (Theresa Jurls), Abby (Patricia Beetschen), Cotton (Angela Berry Koch), Midnight (Ruth Bruno), Crystal (Sue Fabian), and Salem (Sherri Salazar)

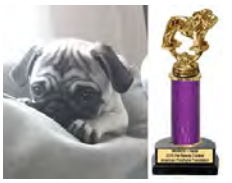
Cutest Name: Three (3) the goat (Frankie Huffman)

Beach Beauties: Holly the crab (Jane Pannor) and Mr. Oboma the fish (Andrew Crask)

Cutest Little Furry Friend: Tiger the hamster (Heather Scattergood)

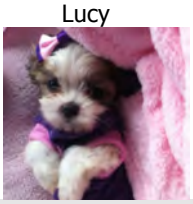
All entries received an APF Pet bandana just like the one Callie Journey is wearing in the photo.

Winner Hazel (Judy Phelps) Winner Callie (Amy Simon)

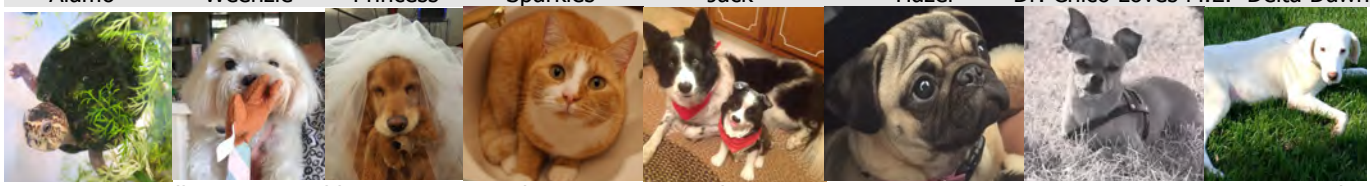



Silky Sue Chicken Kahnee and Gabriella Lucy

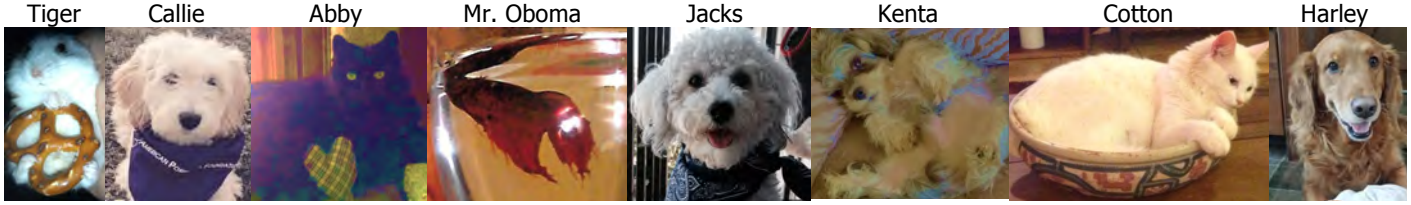




Alamo Weenzie Princess Sparkles Jack Hazel Dr. Chico Loves M.E. Delta Dawn



Tiger Callie Abby Mr. Oboma Jacks Kenta Cotton Harley



Daisee Mae Oso Holly Yngwie King Louis Carson Skye Midnight Cody

Salem Sofia Crystal and Bella Zamboni Dexter Three Eben and Bentley

PHILADELPHIA SUPPORT MEETING

Hosted by **Ariel Lager with Porphyria Expert, Dr. Manish Thapar**

Hear a presentation on porphyria, current and emerging treatments and share your experiences!

1528 Walnut St, 21st Floor, Philadelphia, PA 19102

Saturday, June 11, 2016 3:30-5:30 PM EST Bring Family and Friends!

RSVP by Phone: 215-498-9002 or Email: alager@ces-ltd.com

***Jean-Baptiste Roberge*, "Seizing the day even if it is raining outside."** Throwing a soccer ball into the goal has never been something easy to do for me, because when I was a kid, I never had the chance to go outside with friends and to simulate a football tactic. I just couldn't.

I still remember the summers in the countryside, as an 8 year old boy, trying to explain to a young day camp monitor that I could not play with the rest of the group on the beach. I still remember the judging look on my high school gym teacher's face when I tried to explain that I should stay in the shade of the trees while the others were scoring points on the soccer pitch. I still remember the feeling of guilt after cancelling a trip to Iceland, because I was terrified by a never ending sunset and the comments of my brothers telling me that all this was in my head.

I met an internist who ordered a few precise and unusual blood tests. He later met me with an internal medicine resident. He told her to take advantage of the interview because I would, in all likelihood, be her only case of that condition in her entire career.

I am a 21 year old young man from Québec, Canada studying medicine at McGill University in Montréal. Since last January, I have been diagnosed with Erythropoietic Protoporphyria (EPP), an extremely rare genetic disease that explains the symptoms I have had since a very young child, symptoms without any visible manifestations, symptoms that only I can feel, namely, severe skin pain accompanied by a burning, stinging, and tingling sensation as soon as my face, arms, or hands are exposed to sunlight. Since I have absolutely no physical findings visible to the naked eye, this cutaneous photosensitivity is extremely difficult to explain to others. The most difficult part is that if I slightly abuse the small tolerance to sunlight, this severe skin pain can carry on for multiple hours, nay several days. Nothing helps: sunscreen, tinted glasses, or water in a pool have absolutely no protective effect on me.

Because of my EPP, I have an accumulation of protoporphyrins in my red blood cells. These proteins abnormally react to visible and ultraviolet light, entering an excited energy state that damages my skin tissue and my liver and makes me prone to gallstones and liver failure. Unfortunately, there is no effective way of lowering my circulating protoporphyrin levels. Beta-carotene, cysteine, carcinogenic occlusive sunscreens, and narrow wavelength phototherapy have been tried. Afamelanotide has shown great promise and has been approved in Europe but not yet in the US. Lack of awareness for this rare disease slows down the regulators.

When I was a kid, I would have been happy if at least one person could simply understand me. Awareness for rare diseases such as EPP could mean the world for people affected by them. Even if there is no cure available for my condition, I finally have a justification for my symptoms and a simple way to explain them to others without being judged. As a future physician, I will do the very best I can to be aware of these rare and afflictive diseases.

Summers and their cruel sunbeams, winters and their sparkling snow: everything is against me. Everything? No! I have an ultimate compromise: avoiding the sunlight, wearing long shirts, walking away from the sun, planning on which side of the car I should sit during long trips, even resigning myself to never being very good at outdoor sports, being different, accepting this handicap, and still seizing the day, even if it is raining outside!!!

Read the entire story on the APF website.

PATIENT MEETING OPENS AWARENESS WEEK Louise Schlosser hosted a Patient Education and Support meeting at her home in Placentia, California. The group represented all types of porphyria and enjoyed sharing their experiences with the others. Representatives from Alnylam Pharmaceuticals attended and told the group about their new treatment being researched for the acute porphyrias and explained the research process. The fellowship and support were a joy for all, as was the knowledge they gained. Desiree joined the group via a telephone conference and answered basic information developed by porphyria experts. If you are interested in hosting a meeting in your community, please contact the APF. We will supply you with educational materials, DVDs and other materials. Support groups are terrific! You can meet people in your same circumstance, gain a sense of empowerment and control, talk openly and honestly about your situation and reduce distress, depression, anxiety or fatigue, develop a clearer understanding of what to expect with your health, and compare notes about resources, such as doctors. It is also helpful to turn to others outside your immediate circle, as this can be a valuable resource. Thanks to all the attendees and to hostess, Louise. If you would be willing to also host a meeting, please contact the APF.

JOIN US AT OUR NEXT PATIENT EDUCATION MEETING IN PHILADELPHIA, PA
HOSTED BY MS. ARIEL LAGER
PORPHYRIA EXPERT, DR. MANISH THAPAR WILL MAKE A PRESNTATION ON PORPHYRIA AND ANSWER YOUR QUESTIONS. BRING YOUR FAMILY AND FRIENDS!
SATURDAY, JUNE 11, 2016 3:30-5:30 PM EST

A STORY OF HOPE ***get out your hankie!!!*** Audrey Shering: I was born to a Mentally Retarded Paranoid Schizophrenic single woman (her actual diagnosis.) I remember the first time I felt the pain from the sun, I was 4, my cousins, friends & I were outside, and I couldn't stand the burning on my hands. I wrapped them to stop the burning, but it didn't help.

I was taken away from my mother after horrific abuse and put in foster care at age of 6, temporarily going back and forth from foster care to home, until I was 9 years old when I finally became a ward of the state. The first foster parents were horribly abusive, (back then who listened to kids about abuse?) They lived on a working farm and that's just what I did. I worked all day long in the sun. I would cry and beg to be in the shade or go inside, but I was told it was in my head. This gave them another reason for a beating, I would cry (being just a little child) constantly, especially at night because they wouldn't let me out of bed to get cold compresses or anything to ease the pain. Needless to say, because I was crying, I was keeping them awake, so they beat me with the flashlight they used as a light into my room. I would find anything cool to place my hands on, bed rails, walls, trying to reach for the air blowing in the room, anything. I learned how to muffle my crying over the years, (to this day, I am afraid of being sick or in pain because I worry I might bother someone.) They never took me to the doctor or dentist or anywhere for that matter other than school, so they wouldn't be found out. I even got a beating because the school called to tell them I needed glasses!

They never told my social worker of my physical status, and when I told her what was going on, she wouldn't believe me because the family was supposedly upstanding. Finally, after the final beating, running away for the third time and new social worker, I was taken from the home, and they were shut down. My new home opened a whole new world for me. I tried to do things kids/teenagers do. I went to Myrtle Beach but after only 45 minutes, I had to stay in the rest of the trip. I was hospitalized for 3 days because of the reaction. It was all so difficult.

After all these years, I finally found out about EPP almost 5 years ago. I never heard of anyone else who had the same symptoms as I, NEVER. I found EPP while being housebound due to a reaction by looking up Sun Allergies on the internet. I cried, with tears streaming down my face, pacing throughout my house, I kept saying "this is me." Tears of relief, I am not crazy! I didn't deserve to be beat for this! I have a friend who is a dermatologist, who tested me and said I did not have EPP. I left the office telling myself, I know I have EPP, I KNOW I DO. A few days later, my doctor called and verified that I do have test results showing a positive diagnosis for EPP.

I found the APF and spoke with the Executive Director, Desiree who gave me instructions on how to be tested for EPP. I was tested, and it was confirmed again. Knowing I have EPP, doesn't change my lifestyle, I am still biking, backpacking, hiking, etc., always protecting myself. People tell me I am a very strong person. When others look at my life, aside from EPP, I guess my life has been one challenge after another. I have lived through unspeakable things, and lived in 10 foster homes, and endured so much as an adult, but I have a faith that is unstoppable. It's what we do with the Mountains we face, are we going to go around them, never dealing with the issues at hand or do we blast right through? I have chosen to climb each mountain with strength and courage that the Creator gave me. The Lord has made me very strong, sometimes bullheaded. At times, I bet He shakes His head at me, so then I just tell Him, "YOU made me this way!" Yes, I am strong, only because weakness is not an option; I will not be defeated. My purpose is to help others with EPP! *Read the entire story on the APF website.*

Kathryn Nelson My Porphyria Cutanea Tarda (PCT) experience began seven years ago in Texas. When lesions appeared on my face, forearms and legs, I thought that I had Psoriasis, so I exposed myself to UV rays every afternoon. More lesions developed and the existing ones grew in size. Repeated visits to my Dermatologist resulted in a variety of diagnoses including eczema, hives and a "picking" disorder. I continued to use antibiotic ointments on the most severe patches and, as a result of other health concerns, discontinued my efforts to get a daily dose of UV rays. Over time, the lesions began to shrink but a new symptom developed. My skin darkened dramatically in areas where there were no blisters, and where the blisters had healed, the skin turned white, like vitiligo.

Several months later, I met with Dr. Melissa Costner in Dallas. Most of the lesions and blisters were healed, however, the splotchy dark patches and scarred white areas covered most of my arms, face and large portions of my legs. I described my experiences over the previous three years. She listened closely and then said she wanted to do some blood work. Three weeks later, she diagnosed me with a familial type of PCT. In one minute, all of the heartaches of the previous four years made sense. She listened to me, something the previous doctors failed to do. She believed me when I said I wasn't "picking" my skin and said that rather than affecting areas where I "could reach," PCT was actually affecting areas being exposed to the sun. By reducing the time I was spending in the sun due to my energy issues, I had actually started the PCT healing process.

Today I still have dark patches and white scars, but I have few reoccurrences of PCT. I pay close attention to my medications, particularly since I have other auto-immune disorders. Finding a doctor who listened gave me a sense of empowerment that I continue to rely on today. *Read the entire story on the APF website*.

Melissa Nagin It started as a thought, but over the past year became a reality and the trip of a lifetime. I am 29 years old and have Variegate Porphyria (VP) that was diagnosed 8 years ago. The road to a proper diagnosis was a bumpy one and involved many hematologists, dermatologists and PCPs. I began to blister all over the tops of my hands and my face; my skin also became very fragile and was being cut and bruised easily. My PCP attributed the symptoms to my hiking, but it continued to get worse. On a school break, I saw a dermatologist who biopsied a blister and made a diagnosis of Porphyria Cutanea Tarda (PCT). I was referred to see Dr. David Bickers, a porphyria specialist in New York City. Prior to meeting with him, he asked if I could put together a timeline as far back as I could remember; include where I was living, what I was eating, what medications I was taking, and anything else I could remember. My parents and I met with him and after looking at the timeline and various other blood tests, he made the connection between starting birth control and blisters. Almost 2 years after symptoms, I was diagnosed with VP. At this time, I learned that I was very sensitive to the sun and allergic to the unsafe medications. I was in shock but promised myself not to let my disease dictate who I am and what I can and cannot do. So I took a trip to Tanzania and successfully climbed Mount Kilimanjaro.

(Editor Note: This is not possible for all porphyria people.)

The Lemosho route was our home 8 days. With our head guide, Moses, 2 assistant guides, 2 cooks and about 25 other porters, 5 of us started our journey up the mountain. Pole Pole (slow in Swahili) was a word used often, stepping very slowly as we began our journey to 19,000 ft above sea level. Five camps followed each higher than the other until Camp 6, Barafu Camp (15,019 ft), the camp to summit. We got into bed around 7PM but nerves and excitement about the upcoming summit proved too much. At 11:30PM knock, knock happened. And we all prepared for the summit. Layers of clothing, water, snacks and packs, and ready to go.

Prior to leaving camp our group stood together, held hands and spoke words of a safe climb. It was midnight, and we set out for the summit of Kilimanjaro. Pole Pole, with headlamps lighting the way, we fell into line with the few hundred other climbers hoping to reach the summit. The stars were beautiful. I was left to my thoughts, while trying to continue to breathe and reassure myself I could do this. I started counting steps as a way to keep my mind occupied. Around 6:30AM the sun began to rise, we had been hiking for six and half hours and were 2 hours from the summit. We arrived at Uhuru Peak 19,341 ft above sea level, took some pictures and very quickly turned to head back down. The altitude was a struggle for me, and I was extremely fatigued due to the lack of oxygen. As I started down the mountain I began to think more clearly and make sense of what I had just done.

We arrived back to base camp and headed to our last camp. Sleeping at a much lower altitude felt great and gave us the energy for our last day. We arrived at Mweka gate where we had lunch and celebratory drinks and headed back to Arusha. 45 miles, many gallons of water, self-doubt, friendship, tears, laughter, pain, lots of Ibuprofen, support and encouragement brought me to the top of the world. This trip proved that even though I have a rare, genetic condition, with some extra preparation, lots of sunscreen, proper sun clothing, and lots of snacks, nothing can stop me. Anything is possible! *Read the entire amazing story on the APF website.*

HOUSTON PORPHYRIA CONSORTIUM MEETING

The Porphyria Consortium Leaders (middle photo from l to r) Drs. Charles Parker, Joseph Bloomer, Robert Desnick, Montgomery Bissell, Herbert Bonkovsky, John Phillips, and Karl Anderson, who are directors of the six Porphyria Centers across the country. They met in Houston March 13-14 to share their present and upcoming research, discuss research results and the *Protect the Future* (PTF) program to train future experts. Joining them were PTF doctors and the research coordinators who had worked together for several years but had never met previously, so it was a special time for the whole team. Although the APF staff had also worked with the coordinators, they, too, had never met person to person.

As you will remember, the Porphyria Consortium has won two $5 Million dollar grants and most often the meetings are held in Washington, D.C. to accommodate the NIH representatives who oversee these major grants. The Porphyria Research Consortium was one of only 30 rare disease groups to receive a grant given by the NIH.

There are several research projects you can enter, including the Panhematin study, family studies, the Alnylam study and the Longitudinal study. Your participation is essential. Volunteers are Medical Heros, because without research there are no new treatments, no new advances and no new discoveries. We also will be sending out a survey in the next few weeks that will ask you very pertinent questions. When you receive it, please fill it out and return it to the APF. Many thanks!!!

Megan Parrish I was officially diagnosed with Acute Intermittent Porphyria (AIP) in the spring of 2006. I was a senior in high school and had been plagued since puberty with an "unnamed" illness. It was a relief to finally have a name for the disease, but I was naive about what having AIP meant. I thought with a name would come an easy fix. Previously, I had been diagnosed with all sorts of disorders and had a pill to go with them all. We quickly learned about how medication and diet was a huge contributing factor to porphyria attacks and that I was taking medication and eating things that were harmful. I made big changes in my lifestyle and altered my medications, eating habits, exercise, and even beauty and hygiene products. For several years, I only endured mild symptoms. I went to college, joined a sorority and held leadership positions in other clubs. I had all but forgotten I had porphyria. In 2010 I accepted an opportunity to intern for Heifer International in Romania. It was a life changing experience. I was not sick then and had no idea that soon my life would be turned upside down.

What I refer to as "The Big Attack," happened after I returned home. It began with tingling and numbness and a sensation of rapidly growing and shrinking and tachycardia followed by severe insomnia, nausea and radiating pain like a strand of Christmas lights. I call it the "Alice in Wonderland Effect." Porphyria was so far from my mind, I didn't think about it as the cause. The symptoms became out of control, so I was admitted to the hospital. They were unprepared to deal with my condition. Luckily, my mother had the forethought to contact the APF. Desiree helped coordinate my treatment and how to administer Panhematin. I suffered seizures, infections, paralysis of my legs, severe cellulitis and phlebitis in my arms. I was close to death many times and lost 33lbs in under two months.

Life wasn't easy when I went home. I was angry and confused. It was like I had fallen asleep in summer and awoke in winter. We hadn't even had Halloween and suddenly it was Thanksgiving, the world had kept moving while I was standing still. College started without me and everybody else led normal lives, while I learned to eat, walk, brush my hair, bathe and stand. I was frustrated and hated looking in the mirror, because it just reminded me of what I had lost. I wanted my life back but couldn't have it. Although I battled depression, anxiety, etc., I had surgeries and ports placed and finally improved. I found joy in life and my support group kept me going. I learned to love the person porphyria made me. I savor happiness and store it for the big attacks and sleep and dream of all of you who make life special. Now when I get sick, I'm more aware of my body and am able to call my team at my local hospital and schedule outpatient infusions. I am more aware of all my triggers and I do my best to avoid them. I continue to get monthly to weekly Panhematin infusions to manage my porphyria. I'm determined to have a positive outlook on life.

Read the rest of the story on the APF website.

Andreea Miller I started symptoms in 2010, after my 19th birthday. Every few months, I would get the "flu," which worsened. My muscles and bones would not cooperate for two years. I needed someone to physically force me out of bed. I went to a few urgent care clinics but nothing was diagnosed.

In mid 2011, I began going to both ERs in my town to no avail. At one point I was told I had an ovarian cyst and removal would cure my symptoms. I agreed with everything they said. After removal, I was in even more pain than before. Hydrocodone would make me sick, so I began to be told it was in my head and needed a psychological evaluation and that I was taking away from other patient's time. My mom fought back "What 20 year old WANTS to be sick this badly?"

My condition deteriorated and by 2012, I was having monthly attacks. Soon my grandmother passed away. We were very close so I subsequently had a nervous breakdown and lost hope, but mom thought we should try the ER "one more time."

One doctor decided that gallstones were causing my symptoms. So he operated immediately and removed my gallbladder. Soon, I entered the hospital again for dehydration, malnutrition, etc., and had three seizures and no memory of any of the next three days. When I came to, I was paralyzed from the mouth down and was clearly not faking it. I spent 62 consecutive days in the hospital. After testing, my doctor finally said, "You have Acute Intermittent Porphyria" and explained it all. He said it's not curable, however, there are treatments. I remained paralyzed for a while, but slowly regained functions, like swallowing and speaking, but I am still in a wheelchair. I have attacks monthly, sometimes even twice a month. I attend physical therapy and would be walking if I didn't have regular attacks that practically erase any progress I have made over the last month. If I had a break from the attacks, I would be able to walk again. I always get Panhematin for attacks in my Lubbock, TX hospital. Weekly infusions would help tremendously with attacks, but cannot afford the treatment without being in an attack. *(The APF is working to direct her to an assistance program.)* I have had approximately 85 hospital admissions and spent over 30 consecutive hours going between ERs before I received my diagnosis.

I flew to see Dr. Anderson for the first time in August 2014 to participate in the Panhematin study and have a relationship with a porphyria specialist. Dr. Ede explained the benefits of joining the research. I am now enrolled in every possible study and have no regrets about joining the studies. *Read her entire story on the APF website.*

Kim Littlewood My porphyria was diagnosed in December 2002. I was 4 weeks pregnant and was put on medication that turned out to be unsafe. I began having stomach pains that increased in intensity. The pains worsened, plus, I started vomiting a lot and got very weak. After visiting the doctor, he called and asked me to return. I collapsed and started having a seizure, so my partner phoned for an ambulance and I was taken to the hospital. Fortunately, the doctor on call had seen a case of porphyria and tested me. All of my symptoms increased and I couldn't walk, sit up or speak and was being fed by tube. I was diagnosed with AIP. I stayed in hospital until May 2003, then I gave birth to a healthy daughter and also undertook intense physiotherapy to help me walk and talk again.

Unfortunately, I spent most of the next three years in the hospital with bad attacks. Nothing stopped them, including hormone manipulation and Normosang infusions. I was referred to porphyria expert, Professor Cox, who was unable to stop the attacks. I was admitted for ten more months without stopping so Dr. Cox suggested a liver transplant. I was only 31 with 2 children who needed me, so I agreed to the transplant. At this point, I was still inpatient but the porphyria worsened. I went blind which was a side effect of a rare complication to porphyria where my brain was swelling and I was having constant seizures. My family was called in as they didn't think I'd make it through the night but I did, although I was resuscitated 5 times. I was transferred to Dr. Cox's care where I was put at the top of the transplant list. After the surgery, I felt better than I had in five years. It was amazing as I was virtually pain free. It has been nearly 9 years. Yes, I will always have porphyria as it's in my genes so therefore, in all my other organs but because the liver is genetically not mine, I don't have attacks anymore as it was the liver that couldn't handle the porphyria. Yes, I have to take medication for the rest of my life but the point is I now have a life. It doesn't revolve around admissions. Life is great. *Read Kim's entire story on the APF website.*

PORPHYRIA T-SHIRTS Long and short sleeves, magnets, ribbons, bracelets and all sorts of items are available through the APF. If you are interested in a T-shirt and finding out about the other items, please email Amy Chapman at amy.apf@gmail.com.

Contact the APF at 713-266-9617 to order an Emergency Room Kit or DVDs and extra brochures.
Contact the APF to order a free doctor packet for your doctor or doctors.
Desiree's book, *A Lyon's Share of Trouble,* can be ordered over the APF website online.

MOO'VE IT IN THE MOONLIGHT RACE Once again, Shawn Willis and his family are hosting a fundraiser for the APF in Burlington, NC. He also will be enhancing awareness of EPP, a rare photosensitive disease Shawn has suffered with since he was a youngster. Shawn, who owns a Chick-fil-A in Burlington, hosted a ***Moo've It In the Moonlight Run*** last year and has taken on the challenge to do it again. The Five Mile and One Mile races will be held in the evening to illustrate the difficulty of people who are sensitive to light. If you are near Burlington or want to travel to Burlington and participate in the race, contact the APF for further information. The ***Moo've It In the Moonlight Race*** will be held June 10th at 7:30 PM at the Joe C. Davidson Park. Visit www.cfaraceseries.com to RSVP!

THE UPCOMING PATIENT MEETINGS WILL BE HELD IN PHILADELPHIA, INDIANAPOLIS, SANTA ROSA BEACH, CHICAGO, AND MORE!

IN HONOR It is a pleasure to thank those who donated to the APF in honor of a friend or family member. The gesture speaks much of your respect for that person. We sincerely appreciate your gift in honor of:
Joanne Bower, Donna Malone, Thomas Jacobs, and Connie Gonzalez for **Candace Johnson.**

IN MEMORY The *In Memory* column is very hard for us. We have known many of the people for years and others are new friends or family of our members. We send our sympathy to the family and friends who honored the memory of their loved ones with gifts to the APF. We join them in thanking you for their donations: The Jodee Blanco Group, Inc., Theresa Westrup, Beverly A Goodall, Mary M Heiden, Janis White for **Leona Young**; Lisa Kancsar for **Eugene, R Nielsen**; Ronald and Mary Mistretta for **Margaret Purcell**; Carole E Kuklewski for **Vince E Kuklewski**; Florence Kirshoff and Family for **Bernard Schmidt**; Davida S Hansen for **Jerilee Nickerson**; Lisa D Anderson for **Anne Kilcrease**; Desiree Lyon Howe, the APF Facebook Admins and APF Staff for **JoAnna Floyd.**

What's New at the APF

www.porphyriafoundation.org

Is Your Membership Up to Date? The APF is able to maintain our physician and patient education programs and many other services because of your support. We do not receive government funding to run the APF, rather we receive donations from you, your friends, your family and people interested in the porphyrias. Now we need your support for several programs that are very special.

First, our *Protect the Future* program to train future experts is important to our future health. Without experts, doctors have nowhere to turn for advice and to learn about porphyria. This is a serious problem that we are trying to prevent by training young doctors, but where do we receive funding to do this except for help from our members**.**

Next, we have an enormous physician education program that distributes exceptional educational materials to doctors. Please help us produce these materials.

American Porphyria Foundation
4900 Woodway, Suite 780, Houston, TX 77056

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