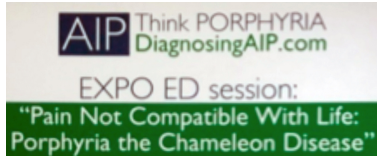


NURSES LEARN ABOUT AIP Dr. Lisa Kehrberg presented on AIP at the American Association of Critical Care Nurses convention held recently in San Diego. Such gatherings are an important venue for our medical education program. During the convention, Dr. Kehrberg taught nurses the etiology of acute porphyrias, prevalence and onset, key signs and symptoms and the diagnostic process. She also shared about her own porphyria attacks and her use of Panhematin treatments to alleviate the attacks. Thank you, Dr. Kehrberg, for your efforts to heighten porphyria education and awareness.



PANHEMATIN



Darryl LaRuu Golan entitled his photo hematin or coke because of the color of hematin. Others have said it looked like crank case oil, thick tea, etc. However, as one person said, "*Panhematin may look odd, but to those of us whose lives were saved by it, Panhematin is PURE GOLD.*"

The APF will send you an updated Panhematin brochure upon request. You can read about Panhematin on the APF website at:

<http://www.porphyrifoundation.com/testing-and-treatment/medications-for-porphyrria/panhematin>.

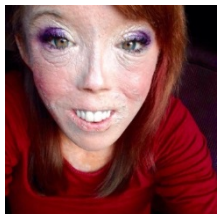
Also, you can read patients' stories and experiences on our website as well at:

<http://www.porphyrifoundation.com/about-the-apf/member-stories>. Please share your own story with us!

COUNTERFIT CHEMICALS Melanotan The FDA issued a warning letter about the illegally internet marketing of Melanotan II as a drug that prevents skin cancer and assists tanning. The FDA has not licensed Melanotan II, and explained: "*There is NO evidence that the product is safe and effective.*" They concurrently gave a blanket warning advising consumers to, "*stop using Melanotan II, an unapproved product.*" European agencies also placed similar warnings. Below is a partial statement from Clinuvel. The entire statement can be read on their website.

Recently Clinuvel has been made aware of members of the erythropoietic protoporphyria (EPP) community discussing the use of unlicensed counterfeit chemicals being offered online as "melanotan I" and "melanotan II." There has been unnecessary confusion regarding these illegal products and I wish to state unequivocally that these substances are in no way associated with Clinuvel's SCENESSE® (afamelanotide 16mg) which has been authorized in the European Union. The "melanotan" chemicals sold illegally online as cosmetic or lifestyle drugs are untested, are unauthorized for human use and are not associated with Clinuvel's drug and development program. These chemicals are of unknown origin and their ingredients and components are uncertain. Further, these "melanotan" chemicals have not been proven to have a similar pharmacological effect to afamelanotide, nor have they been evaluated in clinical trials for EPP or other disorders. A number of pharmaceutical regulatory bodies, including the USFDA, Irish Medicines Board and UK's MHRA, have issued formal warnings against the use of these unauthorized products. Under no circumstances do we encourage any individual to purchase or use the "melanotan" chemicals – there are risks involved in the self-administration of these internet sourced products of unknown origin. This stance has been publicly maintained by the Company for some time. Following the approval of SCENESSE® in Europe, all patients receiving the drug will be monitored via formally approved programs on an ongoing basis for safety and efficacy. Due to the risks posed by the counterfeit chemicals, any patient who has self-administered "melanotan" will render themselves ineligible for treatment with SCENESSE®. It is anticipated that similar measures will be implemented globally.

AMBER PEACOCK & CEP Amber suffers from the ultra-rare Congenital Erythropoietic Porphyria (CEP), with only



a few hundred cases worldwide. CEP is one of the most severe porphyrias. It starts at birth. Skin photosensitivity results in severe blistering, scarring, increased hair growth on sun-exposed skin, brownish-colored teeth and reddish-colored urine are common. There may be bone fragility due to expansion of the bone marrow and vitamin deficiencies, especially vitamin D. Red blood cells have a shortened life-span and mild or severe hemolytic anemia often results. Synthesis of heme and hemoglobin is actually increased to compensate for the shortened red blood cell survival and is associated with splenomegaly. Bacteria can infect the damaged skin and contribute to scarring.

Avoidance of sunlight is extremely important. Blood transfusions to correct anemia occurs in severe cases to reduce porphyrin production by the marrow. Removing the spleen is sometimes considered. Gene therapy may be an option in the future. Amber's poem below is a poignant look into her spirit.

**When she is told her skin is too scarred; I do not hesitate to offer,
That the sun loved her so much, It kissed her more than the rest of us.**

JOSEPH JOSLIN



After I was diagnosed at age four, not much was known about EPP. My mom and I learned by trial and error. It was very important to me to be as "normal" as possible, so I participated in the things that all young boys did. I played baseball, went to the pool, rode my bike, and played outside, even during the day. Before the new photoprotective clothing, I always wore light weight clothing washed in sun protective factor, a hat with a long shade tail down the back that covered my neck and long sleeves. We also took a cooler full of ice and frozen bandanas to cool my skin if I got too hot or started to have a reaction. Coaches and teachers were great about understanding my limits and knowing that I wanted to push past them if I could. There were many times when I had a reaction and suffered pain and the blisters. I even have scars from some of those reactions. But every time I had a supportive family that cared for me and helped

me through with love and laughter. I consider those scars signs of trying to live a normal life. There were, of course times, when I just could not participate or go outside and had to listen to my limits. This only made me want to understand my EPP even more. I traveled to Mayo in Rochester for years where I was put on Lumitene and a sunblock called, Total Cotz, which helps protect me from the harmful UV rays of the sun. I wear all the latest sun protective clothing. But bottom line has to be, people with EPP cannot let it define them. You have EPP. EPP does not have you. I am currently 21 years old. I still enjoy outdoor activities. I was told I shouldn't have tattoos either, but when I was 18, I got one that said, "I can do all things, through Christ who strengthens me." That's how I've always approached my EPP. I am a welder (something else I was told I could never do). I take my Lumitene and vitamin E and D every day, and although I never forget I have EPP, I never forget that I deserve to live the life I want. I want all kids who are growing up with EPP to know something that my mom always said to me. God chose you to have EPP, not someone else, because you are strong enough and you can do it. God chose you, now what will you do with that?

Editor's note: According to his mother, "Joe's positive attitude helped him considerably, but he had difficult times as well. He endured many painful days and nights when I would mother would wrap his hands and feet in ice cold towels. He would run from shadow to shadow to avoid the sun. He was also bullied in school for his EPP and was called awful names. It was hard for him to watch friends do things that he couldn't do or was not invited along. Nonetheless, Joe has always tried to be positive and strong. He is an amazing young man whose great desire is to truly help others, especially those with EPP."

INTERNATIONAL PORPHYRIA CONFERENCE Don't forget!!



The next Congress for Porphyrins and Porphyrias will be held in Düsseldorf, Germany, September 14-17, 2015 at the Capitol Theatre Erkrather Straße 30, 40233 Düsseldorf. This Congress provides a means for experts worldwide to meet to share their expertise and updated research.

AND PATIENT DAY will take place September 13, 2015 at the city Youth Hostel, Dusseldorfer Strasse 1, 40545.

USA PATIENT EDUCATION MEETINGS



Each year the APF host a series of patient education meetings around the country. These meetings give you the opportunity to meet other patients and learn about porphyria. One meeting will be held in conjunction with the American Society of Hematology convention in Orlando, Florida, December 5-8, 2015. Watch your weekly e-news and news on the website to receive details of the meeting: time, place, etc,. We also plan to host meeting in the following cities over the next twelve months: Houston, Atlanta, Los Angeles, Chicago, and New York City. Where possible, other cities will be included, particularly if our members can help by hosting a meeting at their home or local venue.

If you live near these cities and would like to assist us in setting up the meetings or helping with the meet and greet, please contact the APF at porphyrus@porphyriafoundation.com or 866-APF-3635.



American Society of Hematology

Helping hematologists conquer blood diseases worldwide.

The ASH meeting is the premier event in hematology. It will provide attendees with an invaluable educational experience and the opportunity to: review more than 3,000 scientific abstracts highlighting the updates in the hottest topics in hematology, interact with the global community of more than 20,000 hematology professionals from every subspecialty, attend the hallmark Education and Scientific Program sessions Network with top minds in the field. The meeting will be held in Orlando, Florida, December 5-8, 2015. The APF places an exhibit booth at the ASH convention to distribute our physician education materials and brochures to the hematologists, nurses and other healthcare physicians in attendance. If you live near Orlando and are willing to help man the exhibit booth, please contact Yvette at 866.APF.3635.

OUR PROTECT THE FUTURE PROGRAM UPDATE



As most of you know, the PTF program was established to train future experts. These young doctors are trained by our present experts so that their expertise is not lost. We are very proud that this program has become a model for other organizations. We are mostly proud that our young doctors have gained acclaim in the field of porphyria for their clinical expertise, research efforts and knowledge of the porphyrias.

During the past few years, the PTF team has participated in the research endeavors, written grants and major medical journal articles just as their mentors. Without these PTF doctors the future of porphyria treatment would be at risk. We cannot continue this program without your support. Please make a donation to the PTF program. We thank those who have generously provided funding but we need additional funding from our members. We cannot operate this program without funding.

Each newsletter will feature a PTF doctor. This way you will know more the men and women who will advance porphyria in the future. Hopefully, you will help the APF train more young experts.

Dr. Larry Liu is this issues PTF featured physician. Dr. Liu, who was one of the first PTF doctors, is a specialist in gastroenterology, liver diseases and transplant hepatatology at Mount Sinai Hospital in New York City. Dr. Liu oversaw the first liver transplant for an AIP patient in the USA when a transplant became necessary for his patient. Dr. Liu earned his B.S. in Biology at the University of the Philippines and an M.D. at the University of the East Ramon Magsaysay Memorial Medical Center. He completed his internship and residency training in Internal Medicine at St. Luke's-Roosevelt Hospital Center and fellowships in gastroenterology and general/transplant hepatology at St. Luke's-Roosevelt Hospital Center and The Mount Sinai Medical Center, respectively. Prior to his return to Mount Sinai this year as an attending, Dr. Liu had been the Assistant Training Director at both the Department of Medicine and the Division of Gastroenterology at Cebu Doctors' University Hospital (Philippines). We are very proud that a brilliant physician, like Dr. Liu, has gained tremendous knowledge in the field of porphyria. Thank You, Dr. Liu.

DIAGNOSIS IS OFTEN DIFFICULT



After finally preparing her test samples for shipment, Amy Shelby hugs it good bye. The process was long and exhausting for her, because she was ill and exhausted from the process of trying to discover what was wrong with her while preparing the samples to ship. Her previous tests were not handled correctly at her local lab, so she decided to ship the samples directly to the University of Texas Porphyria Laboratory. Many people do the same instead of having their samples handled by a local laboratory. With the help of the APF and UTMB, she should have an answer soon.

You can make diagnosis easier on yourself by having the APF send your doctor a very comprehensive doctor kit that shows how to diagnose and treat properly, please contact the APF for help at Porphyrus@porphyriafoundation.com or call 866.APF.3635 or 713.266.9617.

21st CENTURY CURE ACT

We are proud to announce that this act has passed the House of Representatives. The APF was very active in promoting the approval of the CURE ACT which is a non partisan effort to help modernize and personalize health care, encourage greater innovation, support research and streamline the system, including FDA drug approval. Please write your Senators in support of this bill. We need new and better treatments, so we can participate in seeing that these treatments are approved timely. Write your Senator today.

IN MEMORY AND HONOR

The APF staff becomes friends so many of our members and their families. Many have been friends for decades. It is very hard for all of us when our members pass on and their families are in grief. Please know that we express our sincerest sympathy to you and your loved ones. Thank you for honoring their memory with a gift to the APF. It is also a joy to honor those members who are so appreciated by their families that they choose to honor their loved one with a gift to the APF.

IN MEMORY

Phyllis K Spiers for **Bradford Leigh Stults**; Carolyn A Cunningham for **Sue Conway Hutchens**; Mary E Alfrey for **Mary Jane Alfrey**; Stephanie J Adler for **Melinda M Marcalo**; Ralph M Gray for **Fred L Gray**; Marie Sidoti for **Frank Nicchio**; Mary Crown for **Mary Hargett Crown**; Bethany Maricle for **Anthony Hicks**; Bethany Heath for **John Saulmon**; Linda Davis for **Jenny Eberhardt**; Thomas W Walsh for **Jane Walsh**; Susan E Yeager, Lois Roper, Kimberly Keith, Rebecca May, Norman Mah, Darrell Johnson, Ken and Barbara Ahrens, Deborah Cleveland, Emma Held, Smith and Hannah Held, Molly Held, Marilyn R Van Duyn, Judith and Kenneth Stoffer, Georgianne and

Frank Hall, Jared J Tappero, M Colleen Bonner, Bill and Dolores Rogers for **Daniel J. Pudlicki**.

IN HONOR

Sally Curtis, Jan Marsh Claudette M Owen, Vernon Middle School for **Cason and Caul Cook**; Elaine E Sasso for **Elizabeth Britton**; Carole K Hedman for **Dr. Karl E Anderson**; Sharon I Koch for **Jagger and Jake Liguori**; Tina and Walter Dias, Jr. for **Scarlett Dias**; Donna L Payton for **Sabrina**; Vincent Poleo, Jr. for **Candace Johnson**; Anne Johnson for **Candace M Johnson**; Desiree Lyon Howe for the Porphyria Consortium: **Drs. Anderson, Phillips, Bloomer, Bonkovsky, Bissell, Desnick and our PTF doctors**.





The information contained on the American Porphyria Foundation (APF) Web site or in the APF newsletter is provided for your general information only.

The APF does not give medical advice or engage in the practice of medicine. The APF under no circumstances recommends particular treatments for specific individuals, and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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What's New at the APF

www.porphyrifoundation.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.

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ABC News, Good Morning America and ABC Nightline aired segments on EPP and featured Savannah Fulkerson and her mom, Andrea. Eleven year old Savannah told the viewers about the difficulty of having EPP and how she longs for a cure. The show also gave the viewers a glimpse of Scenesse, the new revolutionary treatment for EPP that awaits FDA approval in the USA and is approved in Europe. The **ABC Nightline** program also featured esteemed porphyria expert, Dr. Robert Desnick, Director of Human Genetic at the Mount Sinai School of Medicine and member of the Porphyria Research Consortium. The networks have been very sensitive to our cause to enhance awareness and promote better treatments for EPP and all porphyrias. Thanks to Dr. Desnick and the Fulkersons for their participation in the series of programs.



LOCAL MEDIA The APF asked EPP people to contact their local community health and news reporters after the big national stories on EPP. Our strategy was that local networks would air stories on the EPP and the new treatment Scenesse. We have had too many to list but noted a few below:



Topeka News Lots of local news stations aired stories about EPP. Ten year old, Siam Ball, was the subject in the Topeka, KS news. Si had symptoms at age 3, but it took a year to get a diagnosis. At first, she had no visible symptoms, only unrelenting pain until she began having red blotchy hands and third degree burns on her nose, chin and lips. She uses lots of zinc oxide and titanium and clear zinc oxide for protection, as well as UPF clothing and Sunguard by RIT and the long sleeves and hats, hand shields etc. Like other youngsters, she loves to dance, sing, bowl and play MineCraft but has to wait until evening to play outside. We are grateful that Siam shared her story with her community. We hope all will follow her wonderful example.



Winston Salem News and Fox TV featured Dr. Herbert Bonkovsky speaking on EPP and Afamelanotide. Since Dr. Bonkovsky was one of the researchers who conducted the Afamelanotide/Scenesse clinical trials, this was a very special presentation.

THE SHADOW RACE



The Cooks in Vernon, Texas are an inspirational family. Parents, LeeAnn and Chris have repeatedly initiated opportunities to advance porphyria awareness and fundraising for the APF to help their sons, Cason and Caul, who suffer from EPP. First, they devised and hosted Hat Day in the brothers' school. The boys made presentations about EPP at school and asked that everyone wears a hat and bring a dollar for the APF. The first Hat Day expanded and now the whole town is involved, including schools, churches and even businesses. Now Mom, LeeAnn, has created the Shadow Barrel Race to benefit the APF.

Barrel racing is a popular rodeo sport in the West and one that LeeAnn enjoys. In a Barrel Race, barrels are set in a pattern and horses and riders complete the pattern. The rider who completes the race in the fastest time wins the prize. LeeAnn named the event *Shadow Race* because EPP people are often called, "Shadow Jumpers." They are so named because they jump from shadow to shadow to hide from the searing sun.

THE SHADOW RACE will be held on NOV 14, 2015 at the WCEC Indoor Arena in Vernon, Texas starting at 11 AM for Exhibitions and opens at 2 PM. Prizes, including a \$1,800 cash prize, will be awarded. Donations for the race are already being given by the community. Everyone is invited to participate. Thank you, Cook family for playing such an important role in porphyria awareness and the APF. Cason and Caul feel this verse is their own and for all who suffer from EPP: ***Psalm 121 5-6 The Lord watches over you, The Lord is your shade at your right hand. The sun will not harm you by day nor the moon at night.***

THE "MOVE IT IN THE MOONLIGHT RUN" In Burlington, NC, August 28, 2015.



Shawn Willis is a dynamo in everything he undertakes. He is the owner of the Chick Fil-A stores in Burlington, NC. He makes an annual trek to Africa for mission work in Uganda, sometimes even traveling twice a year. He volunteered to participate in the EPP trials which are now leading to FDA approval for the new treatment Scenesse.

Early on in my marriage, Lori and I decided that the sun was not going to keep us from living as normal a life as possible. She has always been a source of strength for me. When she sees a way for me to participate in fun activities, she does whatever it takes to make it happen from USA mountains, to Belize and Africa. On August 28, Shawn hosted the MOVE IT Moonlight Run for porphyria awareness to help fund the APF educational programs.



Results from the pivotal Phase III studies of SCENESSE® (afamelanotide 16mg) in EPP have been published in the *New England Journal of Medicine* (NEJM), 2015, vol 375: 48-59. *NEJM* is the most prestigious medical journal in the world. Editor's note: To me, because of the importance of the *NEJM*, the publication of this article is very significant to the future of EPP education and the drug approval. Please read the entire article.

Dr. Robert Desnick, Dean for Genetic and Genomic Medicine and Professor and Chairman Emeritus of the Department of Genetics and Genomic Sciences at Mount Sinai School of Medicine, New York, and the corresponding author for the NEJM paper says, "*The trial results show that the afamelanotide treatment transforms the lives of EPP patients, in essence that is the ultimate goal of having a company and academia working on new technology for 10 years.*" He continued, "*I'm optimistic that afamelanotide will be available to US patients in the future and delighted that European patients will soon have access to a much needed treatment.*" Dr. Desnick serves on the APF Scientific Advisor Board, the Porphyrin Research Consortium and was an investigator in the Afamelanotide clinical trials. Prof Paul Wilson, Emeritus Professor of Internal Medicine, Netherlands Porphyrin Centre, Erasmus MC Rotterdam, and senior co-author of the *NEJM* paper says, "*Despite more than 40 years in the field it was only while participating as a senior physician in trials with afamelanotide that I gained insight into the major restrictions that EPP places on the daily activities of patients. The effect of afamelanotide on diminishing these restrictions and on patient quality of life is dramatic – even more dramatic than has been captured by the trial assessment tools – and a great advantage of the drug is that side effects are minimal. The approval of afamelanotide by the European Commission following these trial results represents a major breakthrough for EPP patients. As European porphyria physicians we now enter the next phase of making the drug available to our adult patients.*"

RESEARCH VOLUNTEERS / MEDICALS HEROS



Sharon Dill made the decision to participate in the porphyria research studies for the first time. At the behest of the APF, she wrote about her experience, *I recently travelled to UAB Birmingham to enroll in the Alnylam clinical trial. I had just spent 18 days in the hospital due to a severe attack and wasn't sure I was up to the trip. Despite still battling various symptoms, I am glad I made the trip and enrolled in the clinical trial. The APF staff was very helpful in coordinating my visit. The UAB Birmingham staff was very friendly and professional. Dr. Bloomer was great; he spent close to two hours with me and my family discussing Porphyria, answering our questions, and discussing the various research projects and clinical trials. I left feeling like I had additional allies and advocates to lean on to help me manage this horrible disease.*

I would encourage anyone who qualifies to please enroll in the clinical trial. Several people have posted that flying, with all of the lines and waiting, would be too difficult for them. I literally understand how you feel! I utilized the wheelchair services which eliminated the long security lines and also the long lines to get on the airplane. There was no extra cost, just an appropriate tip to the staff member who assisted me.



Becoming a research volunteer is the greatest action you can take for your family, other patients and yourself. Research is the Key to Your Cure. There are a number of research projects ongoing. Some require travel overnight, others don't even require you travel at all. Rather, you are asked to fill in a very comprehensive questionnaire. Then there is also a Panhematin study that requires that you travel for a few days to the University of Texas Medical Branch Hospital and Porphyrin Center.

Porphyria friends and research volunteers Amanda Boston and Tara Cantley are on their second round of research visits for the Alnylam and Panhematin studies. The two decided to make their appointments at the same time and make a fun trip of it. The photo of Amanda left and Tara right with Dr. Karl Anderson, Porphyrin Center Director, is only one of a number of photos of the trip.

Keisha Johnson (above) also participated in the Panhematin and Alnylam studies. On Facebook she refers to herself as Keisha "So Blessed" Johnson, because she feels blessed to have survived serious attacks and is blessed beyond measure to be alive. She, like Tara and Amanda, is active in enhancing porphyria awareness in her community and through her Facebook page.

YOU HAVE THE OPPORTUNITY TO ADVANCE PORPHYRIA TREATMENT BY JOINING A RESEARCH STUDY. NOTE: The Longitudinal Study does not require that you leave your home.. The Alnylam study only requires you be gone one day and the Panhematin study a few days. This is not much to ask of our members considering that a cure may be the end result. Please contact Natalia or Jessica at the APF office and volunteer for one of these important research efforts. You, too, can be a medical hero to your family and to all others who need a cure.

MICHAEL BOONE VOLUNTEERS FOR RESEARCH Michael Boone volunteered for research studies.



Below is his experience in his own words.

In late 2008, after a year long battle, I was diagnosed with acute intermittent porphyria (AIP). At first, I was relieved to finally have answers. Then, I learned how little there was that could be done with the disorder. I wasn't the first in my family to be diagnosed. In the late 1950's my great uncle was diagnosed and then died of the disorder. My grandmother would follow in the early 60's at the young age of 28. My mother was also diagnosed in the mid 1990's. Needless to say I thought I understood the seriousness of the situation, but after learning what my treatment options were, I became nervous. After all, I'm married and have two children. How was my ability to support them going to be affected. I did some research on the disorder and stumbled across the American Porphyria Foundation. Through conversing with them I learned of some opportunities to help find better treatments and, maybe, a cure. I jumped at the chance with more concern about my children having the gene than with concern about myself.

The first study I enrolled in was simple and straight forward. It required no travel and only one time did I have to send them any samples. It was simply blood which was drawn at my local doctor's office and then mailed off to Salt Lake City. The Longitudinal Study is a simple study and I strongly encourage everyone to take part in this study. It was through this study that I was able to get gene testing done at no cost to me. Now, I have concrete proof of my diagnosis. I am still in the study and once in a great while fill out more papers with questions about how I am doing. Like I said – simple and straight forward.

The second study I took part in was the Panhematin study. This study required me to fly to Galveston, Texas and stay there in the hospital for four days. The research grant paid for all of my travel expenses and there was of course no in hospital expenses for me to worry about. The APF arranged all the travel. Again, this study had a simple procedure. Once I began feeling as though I had an attack coming on I contacted the foundation and they made the travel arrangements. The next day I flew into Houston Hobby Airport where a car service picked me up and drove me to University of Texas Medical Branch in Galveston. This particular study was a double blind study. That means that neither I, nor the doctors and nurses know if I was getting the Panhematin or a placebo. Only the pharmacist knew. In order to keep the secrecy I had to wear a blindfold, the tubing and medicine was wrapped in foil, and a sheet was also placed between myself and the bottle of whatever I was getting. This happened once a day for four days, and I was also on normal saline with 10% dextrose constantly while I was there. In all my experience with this study was good. Things went smoothly and before I knew it, I was on my way back home to Colorado. Thanks for your participation, Michael. You are a Medical Hero to all with porphyria.

HANDS ACROSS THE WATERS Upon hearing of the plight of a young man in Pakistan who was in the ICU



with a serious AIP attack, our APF members wanted to help him any way we could. We promptly reached out to our Facebook members in Pakistan and asked if they could visit or contact the young man and his family. The next morning, Asif Abbasi, who has EPP, contacted the family at the Aga Khan Hospital in Karachi. He assured them that he would visit as soon as he could arrange the visit. You see, Asif has EPP and is very photosensitive. Thus, venturing out into the temperature of 110 and the intense sun is not easy. Regardless, Asif made the long trek to the hospital, met the family and brought the young patient a bouquet of flowers with the following note:

These little flowers are rising and blooming. It's the world's way of saying, Get Well Soon. From, Desiree and the APF. What a thoughtful action on Asif's part and a meaningful way to allow us to stretch out our hands and prayers to the young man in ICU. We also want to thank Waheed Butt, another Facebook member from Pakistan. He contacted the family as well and expressed our concern. Dr. Karl Anderson also kindly guided the doctors, as he has done many times for national and international patients whose doctors who lack porphyria expertise. The APF receives requests for assistance worldwide and do our best to help. You can help, too.



DOING WHAT SHE LOVES A Full Sun Run To fellow EPP-ers! My name is Cierra Nicole, and I love to run!



Today I completed the Broad Street 10-miler in sunny, 80 degree Philadelphia! This was my first full-sun race, and it was brutal to be covered from head to toe, but I survived! I modified an already ridiculous hat to run the race, but it worked really well!! I got a lot of funny looks, but my friends and family were super supportive, and I feel great about not letting the sun ruin this event for me! This is a photo of me at the finish line. I hope you all have a great day and find ways to stay safe and out of the sun while doing what you love!!

CONGRATULATIONS! It is inspirational to all to read how people cope in the face of the enormous adversities.