AMERICAN PORPHYRIA FOUNDATION

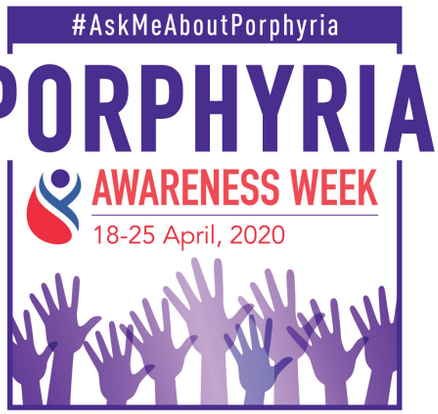
1st Quarter, 2020

PORPHYRIA AWARENESS WEEK

2020 APRIL 18–25 #ASKMEABOUTPORPHYRIA

Porphyria Awareness week is an opportunity for you to create awareness in your community! We strive to dedicate this week to promote Porphyria, reduce the stigma associated with porphyria through education and provide support for those affected.

The American Porphyria Foundation is here to support you with ideas, brochures, materials, social media files (including Logo Files, DVDs, Porphyria Fact Sheets, Press Release – and any other support that you may need to raise awareness about Porphyria in your community, to the general public or to physicians. In recent years, many of you have participated in health fairs, educational seminars, fundraising and various media events. As we prepare for Porphyria Awareness Week, we want to encourage you to enhance and raise porphyria awareness within your local communities.



The American Porphyria Foundation will continue to partner with other international porphyria advocacy organizations to increase awareness around porphyria.

What are your plans this year for Porphyria Awareness Week? We want to know - Send your plans to Iany Schneider, APF Office Manager, via email at iany@porphyriafoundation.org.

WHAT CAN YOU DO?

Wear purple for Porphyria! Some have had a class or an office wear purple for the day in support of porphyria.

Educate friends and family. Send an email, a social media post, or send a letter about your experience with porphyria. This is a great time to talk to a class or host a lunch and learn.

Tell your story to local media. Help others by spreading your experience. Television, newspapers, community magazines are looking for people who have undertaken the challenge with a rare illness.

Help others by sharing knowledge about porphyria with your community, including your family members, friends and the physicians in your local hospitals. Suggest that they host a seminar or a local meeting where you can hand out materials.

Share your story on social media. It is an easy and effective way of getting porphyria in the public eye.

Assist at medical conventions or health fairs to educate laypersons and physicians on porphyria. Ask your hospital or doctor if there is a local meeting where you can hand out materials or tell your experience. Befriend your physicians, and they will share their newfound knowledge of the disease.

Volunteer your talents or skills to help achieve the educational programs of the APF. Interested in hosting a patient education meeting? Contact the APF today!

Purchase APF Merchandise. See the APF website for shirts and other APF products.

Learn how to be an advocate in your daily life and share your knowledge everywhere.

START PLANNING NOW FOR
PORPHYRIA AWARENESS WEEK
APRIL 18–25, 2020

HEME BIOSYNTHESIS AND THE PORPHYRIAS 2020: Consensus Diagnosis, Variant Disorders, New & Emerging Therapies

Registration on www.porphyriassymposium.org

The American Porphyria Foundation and the Porphyrias Consortium (PC) of the NIH-supported Rare Diseases Clinical Research Network (RDCRN) will host a 2.5 day educational symposium titled, "Heme Biosynthesis and the Porphyrias 2020: Consensus Diagnoses, Variant Disorders, New & Emerging Therapies" June 26-28, 2020 at the Hyatt Regency Schaumburg, near Chicago, IL.

This educational symposium will focus on recent research findings in heme biosynthesis and advances in the diagnosis, management, and treatment of the porphyrias. The program will include American and international experts who will describe the clinical manifestations of each porphyria and the latest advances in their diagnosis, management and treatment, including newly approved and emerging therapies. Patients with each of the major porphyrias will be interviewed for patient perspectives.

This symposium is designed for physicians, especially hematologists, gastroenterologists, dermatologists, neurologists, geneticists, and emergency medicine practitioners, as well as researchers, predoctoral and postdoctoral fellows and junior faculty who are interested in heme biosynthesis and the porphyrias. Patient advocates are also welcome to register for the scientific program.

WE ENCOURAGE YOU TO INVITE YOUR PHYSICIAN TO THIS IMPORTANT CONFERENCE!

PATIENT SESSION A concurrent patient day will be held on Sunday, June 28th, 10am-3pm. This will be a special event with multiple expert physicians presenting the latest information on the porphyrias and emerging treatments. An "Ask the Experts" session will enable you to bring your questions to an entire panel of porphyria experts! Visit www.porphyriassymposium.com to learn more. Registration is FREE!

SPECIAL MEDICAL MEETING: HOMOZYGOUS DEFICIENT ACUTE INTERMITTENT PORPHYRIA (HDAIP)

The APF and the Porphyrias Consortium hosted an unprecedented half-day medical meeting January 18th. The purpose of the meeting was to convene world-renowned porphyria experts for a case study on an ultra-rare progressive form of Acute Intermittent Porphyria: HDAIP – Homozygous Dominant Acute Intermittent Porphyria. Physicians from the US gathered in Bethesda, MD, with international experts joining by Skype.

They discussed current literature, review currented cases and considered potential therapeutic and quality of life possibilities. There are two known cases currently in the US, and only several more across the globe.

This meeting was sponsored by friends and family supporting Kam Kadinger, age 3. Kam's family is grateful to the dedicated physicians who gathered to discuss HDAIP. "We don't know what the future holds for Kam," shared his mom, Amanda Jordan, "but we do know that we made a difference today by bringing together the greatest minds in Porphyria."

It was truly an incredible experience. We are grateful to the expert physicians for their dedication and expertise.

(Pictured: (l-r, top)Desiree Lyon; RJ Desnick, MD, PhD; Amanda Jordan; K. Anderson, MD; H. Bonkovsky, MD; M. Kazamel, MD; Kristen Wheeden; (l-r, bottom) S. Keel, MD; A. Lion, DO; A. Dickey, MD; M. Yasuda, MD; J. Phillips, PhD; (not pictured) B. McGuire, MD; N. Dixon, MD)

PROPHYLACTIC HEME TREATMENT

Prophylactic heme treatment is a measure taken to prevent porphyria attacks from occurring. Panhematin®, the first FDA-approved treatment for the acute porphyria, is often administered as a prophylactic treatment. This abstract, published by H. Bonkovsky, MD (Wake Forest Baptist Medical Center, Winston-Salem, NC) helps to explain this use of Panhematin®:

"Acute intermittent porphyria (AIP), an autosomal dominant inborn error of metabolism, is the most common and severe form of the acute porphyrias. Attacks of severe abdominal pain, often with hypertension and tachycardia, are cardinal features of AIP, often requiring hospital admissions. Frequent recurrent attacks, defined as > 3 attacks in one year, during which at least one attack requires intravenous heme therapy, are associated with significant morbidity, lost productivity, and health care burden. We report two patients with such frequent attacks of AIP, who have been managed with prophylactic heme therapy on a weekly basis. We observed a 100% decrease in acute attacks and inpatient admissions in one subject, and a 75% decrease in the other. We also observed a significant decrease in the number of emergency room visits. The decrease in number of acute attacks requiring hospital admission was associated with significantly decreased health care costs and improved quality of life. Reduction of both emergency visits and hospital admissions decreased the utilization of health care services. Outpatient weekly infusions were also associated with better re-imbursements and reduced overall costs of health care. Both our subjects endorsed better symptom control, quality of life and better understanding of disease. Prophylactic heme therapy, through a multi-disciplinary approach, decreases the incidence of acute attacks, decreases health care costs and leads to better patient satisfaction and quality of life."

RESEARCH OPPORTUNITY!

If you are currently receiving prophylactic heme treatment, you may be eligible to participate in the ongoing Panhematin® Prevention Study, please contact Edrin Williams, Director of Patient Services, for more information email: edrinw@porphyriafoundation.org or 301.347.7166.

GIVLAARI UPDATE

Givlaari (Givosiran) is indicated for the treatment of adults with acute hepatic porphyria and is currently available. Contact your physician to discuss this as a potential treatment option.

Process:

1. Make an appointment or talk to your physician about treatment with Givlaari.

2. Initiate the START FORM, available at www.givlaari.com. It can be completed during an office visit or via email. There is a section for each the patient and physician.

3. Contact Alnylam Assist for assistance with understanding your benefits, financial assistance options, information on treatment and to facilitate product orders.

The American Porphyria Foundation is available to help if you have questions about this process. A brochure will soon be available to share with your doctor.

Why the name change? People have asked...are Givlaari and Givosiran the same thing? Yes, Givlaari and Givosiran are interchangeable names for the same medication. This treatment was called Givosiran during the research and development process including the Phase 2 and Phase 3 clinical trials. It was named Givlaari after the FDA approval on November 19, 2109 and it became a commercial product.

SCENESSE UPDATE

Clinuvel is focused on bringing Scenesse to the US. After the much-celebrated FDA approval on October 8, 2019, they went right to work. Preparations include executing FDA mandated post-approval requirements, developing the distribution process, and negotiating arrangements with insurance companies. The APF delivered a comprehensive report, including over 350 participants, with patient location and insurance information. We will offer an update on the availability of this treatment as soon as we have one.

MT-7117/MITSUBISHI TANABE PHASE 3 CLINICAL TRIAL

The positive results of the Phase 2 clinical trial last year paved the way for a Phase 3 trial. Stay tuned for detailed information from the American Porphyria Foundation regarding this exciting upcoming trial.

THE PHASES OF A CLINICAL TRIAL

PHASE 1 Researchers test an experimental drug or treatment in a small group of people for the first time to evaluate the treatment's safety, determine a safe dosage range, and identify side effects.

PHASE 2 The experimental drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety.

PHASE 3 The experimental study drug or treatment is given to larger groups of people to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the experimental drug or treatment to be used safely.

PHASE 4 Post-marketing studies, which are conducted after a treatment is approved for use by the FDA, provide additional information including the treatment or drug's risks, benefits, and best use.

PANHEMATIN® AND NORMOSANG — ARE THEY THE SAME TREATMENT FOR ACUTE PORPHYRIA?

You may have noticed that Panhematin® (hematin) is used in the USA and most recently in Canada, while Normosang (heme arginate) is used primarily in rest of the world. Are they the same treatment? If not, what are the similarities and differences?

Both Panhematin® and Normosang are manufactured by Recordati Rare Diseases, based in Milan, Italy. Both are used as treatment for acute porphyrias and both are infused, using an IV, PICC line or PORT. Their appearance is also similar, I describe it, "it looks a bit like crank case oil, but the effect is like pure gold!" Despite their dark appearance, they are both lifesaving and very effective treatments.

Normosang is a concentrated hemin for injection solution to which arginine is added as a stabilizing agent. The addition of arginine in Normosang makes a difference in the stability between Panhematin® and Normosang.

PANHEMATIN® also is a hemin for injection, which is used to halt attacks of acute porphyrias. It is also used to prevent attacks. Although dosing instructions to stop attacks are on the label, instructions to prevent attacks are decided upon by your doctors, because they are uniquely aware of your case and needs. Your doctors decide how often you should receive Panhematin® to prevent attacks.

Since attacks of porphyria can progress to a point where irreversible neuronal damage can occur, doctors want to stop the attack as soon as possible. Thus, experts recommend that PANHEMATIN® and NORMOSANG be used soon after the attack begins to prevent the attack from reaching the critical stage of neuronal degeneration. Neither NORMOSANG nor PANHEMATIN® are effective in repairing neuronal damage so the importance of rapid treatment is important.

GLOBAL NEWS

The APF has received requests for help from patients and physicians in 76 countries around the world. When we receive these requests from patients, most have no information about the porphyrias except what they can Google — if they have access to a computer. Most have no access to a knowledgeable doctor, a diagnosis, or treatment. No one to help and few to care.

Thanks to an international donor, the APF can help assist every person who reaches out to us through our Global Program. We provide them with information relative to their type of porphyria and a doctor's contact information if there is a knowledgeable doctor in their area. We have acquired the names of 3,600 US doctors and 732 international doctors who have treated the disease. Finding a porphyria doctor is not an easy task in the US, much less in the outermost reaches of the world. Regardless of how far away the patients live, our Porphyrias Consortium of experts gladly consult with doctors around the world when they need help.

One of the biggest ways we can help is by assisting with the creation of support groups in each country. The Mexican Porphyria Society has become a full-fledged viable organization. Now we are working with Eileen Hudson in Chile. Eileen is a dynamo and has already approached the Health Ministry and Rare disease groups in Santiago and created a support group for patients. Gloria Ramirez has joined her in this great project. Anna Rypniewska (EPP) and Magdala Gorbacz (AHP) from Poland have created support groups for their respective types of porphyria and are working together toward the goal of a patient organization. They have planted the seed, which is the most important step. In Pakistan, Abdul Butt continues his efforts to serve the CEP community. He and the APF have been assisting CEP people for several years, even facilitating country-wide conference calls. New on the scene and growing are the acute groups from the Netherlands and Russia.


Eileen Hudson (Chili)


Magdala Gorbacz (Poland)


Anna Rypniewska (Poland)


Abdul Butt (Pakistan)

Our **PORPHYRIA INTERNATIONAL EDUCATION AND SUPPORT** Facebook group, which is now 1,795 strong, is a global source of new caring friends from the uttermost reaches of the world. If you are an international porphyria person and need assistance, contact Desiree Lyon, Global Director of the APF at lyonapf@aol.com.

WHAT IS AN ORPHAN DISEASE AND AN ORPHAN DRUG?

The EUROPEAN ORGANIZATION OF RARE DISEASES (EURORDIS) estimates that as many as 5,000 to 7,000 distinct rare diseases exist and about 80% are genetic diseases.

According to the US criteria, an Orphan/Rare Disease affects fewer than 200,000 people. The definition was created by Congress, when they approved the Orphan Drug Act in 1983. The porphyrias fit into that group.

ORPHAN DISEASES are rare diseases that have not been *adopted* by the pharmaceutical industry, because there is little financial incentive for the private sector to manufacture and market new medications to treat or prevent the orphan disease.

Before the passage of rare disease laws in the United States, most patients diagnosed with rare diseases had no effective medicines because prescription drug manufacturers rarely could make a profit from marketing drugs to such small groups. The Orphan Drug Act created financial incentives that encouraged the pharmaceutical industry to develop new drugs for rare diseases. These include tax credits for costs of clinical research, government grant funding, assistance for clinical research and a seven-year period of exclusive marketing given to the first sponsor of an orphan-designated product who obtains market approval from the FDA.

The Congressional definition was essential to establish the conditions that qualified for the incentive programs. After a great deal of hard work on the part of the APF, Panhematin® became the very first ORPHAN DRUG. We are very privileged to now have three Orphan Drugs approved in the US; Panhematin® and Givlaari for the acute porphyrias and Scenesse for EPP. Considering most Orphan Diseases have NO treatment, we are very fortunate.

Patients with orphan diseases share many common frustrations. For example, many people with rare diseases, like porphyria, endure a lengthy diagnostic journey. Another commonality is that there are so few people with a disease that they live far apart, leaving the patient isolated. They are often forced to travel long distances to visit a knowledgeable doctor; as most primary care doctors have little experience with their disease. Another problem is that misleading or inaccurate information about rare diseases abounds or is presented in such a way that the patient doesn't know that the info is grossly false. Since porphyria is a life-threatening disease, false information is dangerous. Unfortunately, many "Google MD's" or "Couch MD's" report their own conclusions as fact or present medical advice which often has NO scientific basis or may be from an unreliable internet source. Internet information should complement the communication between patients and their doctors, not replace it.

The APF only publishes medical information that is written by renowned Porphyria Experts. You, too, should seek only reliable science-based resources. Having an ORPHAN DISEASE, like Porphyria, is difficult but remember, "Those who know the most-- do the best!!!"

CAMP DISCOVERY

Sponsored by the American Academy of Dermatology (AAD), Camp Discovery offers kids living with skin disease a one-of-a-kind experience. Several EPP Shadow Jumpers have attended and had a wonderful experience. Registration will open soon for Summer 2020 – check it out on www.campforall.org or call the APF for contact information.

FIND YOUR SHADOW 2020 – APPLICATION FORM IS LIVE!

The American Porphyria Foundation and Craig Leppert (EPP) founded Shadow Jumpers in 2017 with the goal of helping children with EPP and their families pursue their passions and dreams despite the sun. Two years of successful years of education and planning has inspired us to introduce a new program this year! We are excited to share…

This year, we are expanding our scope and asking EPP kids to apply with a personalized wish. What is something that you have always wanted to do but have not because of the sun?

Assistance participating in recess, attending a summer camp, playing an outdoor sport or a trip that would have meaning for you and your family. Share with us and let Shadow Jumpers prepare a memory of a lifetime for you and your family!

Find the application under Shadow Jumpers in the "For Patients" section at www.porphyriafoundation.org.

Shadow Jumpers will accept submissions through March 28. Children with EPP, ages 5-17 are eligible to apply.

Recipient(s) will be announced during Porphyria Awareness Week – April 18-25, 2020.

SAFE/UNSAFE DRUG DATABASE QUESTION

Question: Why are acute hepatic porphyrias (AHP) made worse by certain drugs whereas erythropoietic porphyrias are not?

Answer: Because the heme biosynthetic pathway is regulated differently in the liver and bone marrow. Therefore, some drugs, hormones and nutritional factors can affect the pathway in the liver but not the bone marrow.

More detailed explanation: Heme is a component of many different "hemoproteins" that are essential to life, and are made in all tissues in the body. The "pathway" to make heme is a sequence of eight enzymes, and these are found in all tissues. Heme synthesis begins with simple molecules, and the intermediates become increasingly complex as porphyrin precursors (delta-aminolevulinic acid and porphobilinogen), porphyrins and then heme are formed.

Most of the heme made in the bone marrow is used for hemoglobin, and most in the liver for cytochrome P450 enzymes – known at CYPS. Hemoglobin is made only in the bone marrow, and then circulates in red blood cells (erythrocytes) to carry oxygen from the lungs to other tissues. Mature erythrocytes contain but no longer make hemoglobin. CYPs in liver cells (hepatocytes) function mainly to metabolize drugs, hormones and other substances that need to be removed from the body. Smaller amounts of other hemoproteins, including CYPs with other functions, are made in other tissues.

One of these eight enzymes is abnormal in each type of porphyria and, as a result, pathway intermediates can accumulate. Symptoms of porphyria are thought to be due to intermediates that accumulate (delta-aminolevulinic acid, porphobilinogen and porphyrins). Deficiencies of hemoproteins such as hemoglobin and CYPs generally do not occur. Porphyria-related enzyme abnormalities generally occur in all tissues but intermediates accumulate initially only in the liver or the bone marrow.

Look for this image to find the Safe / Unsafe Drug List

Why intermediates accumulate initially in the liver in some porphyrias and in the marrow in others is not completely understood. But tissues have differences in heme synthesis that relate to their different functions. So, although the eight enzymes in this pathway are basically the same in all tissues, their synthesis and regulation is not.

The liver is highly responsive to nutrients, hormones and foreign substances, so it needs to adjust its rate of heme synthesis under different circumstances. Therefore, acute hepatic porphyrias are exacerbated by drugs that increase heme and CYP synthesis in the liver. These drugs include those that are well known "CYP inducers" such as barbiturates, rifampicin and phenytoin. Progesterone, which is the hormone that is especially elevated just before menstruation in women, is also such an inducer. When heme synthesis is induced by these factors, the porphyria-related enzyme deficiency in the liver becomes more significant, and more intermediates accumulate in the liver but not in the bone marrow.

On the other hand, hemoglobin production is a steady process and there is little short-term change in the amount of heme that is needed by the bone marrow. Therefore, erythropoietic porphyrias generally do not change in severity over time and are not much affected by factors that act on the liver, such as certain drugs, hormones and nutrients. Erythropoietic porphyrias are also usually active from birth or even before, whereas hepatic porphyrias are seldom active until after puberty or even later.

Please note: Printed copies of the Safe/Unsafe Drug list are available in the APF store on www.porphyriafoundation.org.

RARE DISEASE DAY 2020

As 2020 is a leap year, February 29th was truly the rarest day of the year! It is a day to raise awareness about rare diseases and the issues patients face. There are over 7,000 known rare diseases affecting 25-30 million people in the US and 350 million across the world. In the US, 90% of rare diseases have no FDA-approved treatment. The week leading up to Rare Disease Day held many special events highlighting rare disease. The American Porphyria Foundation participated in several events – promoting porphyria as eight distinct rare diseases.

RARE DISEASE WEEK ON CAPITOL HILL

The APF participated in events on Capitol Hill. The goal was to advocate for issues related to rare disease and those specific to Porphyria. At the Legislative Conference, we met other rare disease advocates, then lobbied members of the House and Senate alongside our peers. A Rare Disease Caucus meeting was held early in the week, which was an opportunity for a panel of rare disease advocates to highlight major issues facing rare disease such funding for research, diagnostic odyssey, and access to treatment.

NIH

Rare Disease Day at NIH was a day-long event marked by special programming, exhibits, posters. Kristen Wheeden moderated a well-attended session on ***Nontraditional Approaches to Improving Access for Rare Diseases***. For rare diseases, where resources and specialized expertise may be limited, nontraditional methods may help expand access. The APF exhibited during a poster session on our scope of patient advocacy work.

The National Organization for Rare Disorders (NORD) partnered with EURORDIS (European Organization for Rare Disorders) to sponsor multiple events, both in-person and on social media. Members of the APF submitted patient stories via their PATIENT NEWS site to highlight issues that impact living with porphyria.

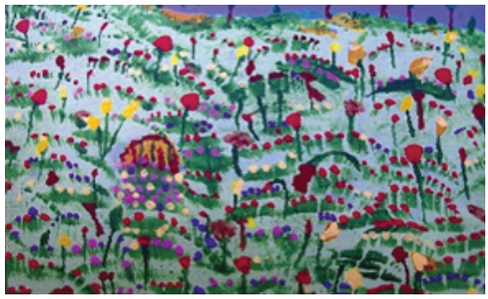
PAIN IN PORPHYRIA VISUALIZED THROUGH ART

Pain is a constant theme in all the porphyrias. This was highlighted in an art exhibition at the International Congress on Porphyrins and Porphyrias in Milan, September 2019. This moving exhibit, titled "Beyond the visible. Visual suggestions and stories about Acute Hepatic Porphyria" is an artistic journey inspired and guided by the clinical symptoms that characterize this disease. The exhibition was sponsored by Alnylam Pharmaceuticals and was in collaboration with the students of the New Academy of Fine Arts. The aim was to raise awareness and to tell the direct experience of patients diagnosed with acute porphyria through varied visual suggestions. The entire exhibit includes 17 artworks. With the help of Alnylam, eight of the original works were on display at Rare Disease Day at NIH, on February 29. The selected pieces highlighted pain in rare diseases and the experience of the pain endured by those living with acute porphyria.

Visualize normal daily life, interrupted by illness. Visualize the ignored pain. A universal story for an apparent absurdity.

Graphic representation of an attack of the disease: pain, confusion, to try to make it easier for the doctor recognize Acute Porphyria.

A project based on the theme of invisibility that invites the observer to go further, to look for a different reality from the one that normally everyone can see.



FIGHTING BACK THROUGH ART

Andrew Crask has done a lot of fighting during his 70-plus years on earth. He fought for our nation in Vietnam, he fights continually with the VA and his local doctors for his health benefits, and he fights daily in his battle with PCT. Andy has found many positive ways to keep the fight going over the years. They include his great sense of humor, his faith, healthy eating, friends and a "good redheaded lady!" One of Andy's recent endeavors is oil painting. He recently shared some of his paintings with the APF staff. They are lovely, happy works that reflect the positive attitude and energy of the artist. Keep the fight going, Andy!

PHILANTHROPY BENEFITTING APF

Zeta Beta Tau – Alpha Kappa Chapter is the world's first and largest Jewish Fraternity, with a focus on "equal rights, privileges and responsibilities for all brothers." In the spirit of community service, the ZBT brothers at the University of Wisconsin – Madison raised over $500 during their philanthropy week for the APF! A sibling of one of the ZBT brotherhood lives with EPP and inspired the fundraising events. The brothers expressed their gratitude to the APF: "We really appreciate the work that you guys do and want to support your cause. Keep up the great work!" The APF is thankful and honored to have the support of such a philanthropic-minded group of young men.

CALL THE APF TO PARTICIPATE!

Patient Education Meetings
March 19: San Antonio, TX
March 21: Tulsa, OK

Exhibits (can you volunteer?):
American College of Medical Geneticists (ACMG)
March 18-20
San Antonio, TX

Digestice Disease Week
May 3-5, 2020
Chicago, IL

CALLING ALL CREATIVES

Over the many years, the APF has contacted TV programs and sent information on porphyria. Well that didn't work, so Desiree Lyon began sending little story ideas. That worked very well with *House*, *ER*, *Medical Mysteries*, and so on. Most recently, porphyria was highlighted on the Fox network show, *The Resident*.

If you have a writing bent, give it a try by writing a short segment about a porphyria patient. Shows need stories. YOU have great ones. Go for It!

Here are some real-life experiences that could be a story. All really happened to patients.

- *A man with EPP, who was very covered to protect his skin, got picked up by police as a suspect.*
- *A young woman's fiancé left her when he discovered AIP could be inherited. It was so sad.*
- *A young woman, who was passed from doctor to doctor, acquired the much-dreaded tag, drug seeker. She finally gave up on a diagnosis until she was near death.*
- *You can think of many more scenarios...just write it and send to your favorite medical program!*

NEW MERCHANDISE IN THE APF STORE!

T-SHIRTS, UMBRELLAS, PRINTED SAFE / UNSAFE DRUGE LIST, AND MORE!

www.porphyriafoundation.org

HAVE YOU SEEN ALL THE PORPHYRIA VIDEOS AVAILABLE ON THE APF WEBSITE?

https://porphyriafoundation.org/patients/media/porphyria-videos

IN MEMORY & IN HONOR

We thank the familes and friends who memorialized their loved ones with a generous gift to the APF.

IN MEMORY:

Sally Braich for **Milo Braich**; Daryl Breeze for **Marlene Breeze**; Michelle Grayson for **Paulette "Binky" Brown**; Charlotte Beck for **Elva Denger**; Mr. & Mrs Diddlemeyer for **Florence Diddlemeyer**; Amanda Cobb for **Jack Donsay**; The Sparks Family for **Henry L. Darsey Jr.**; Alexander Meske, Phyllis Wilson for **Grace Ann Feczko**; Ms. Donnie Flynn for **Carl Flynn**; Gary Horn for **Sandra Horn**; Suzanne Broeman, Angela Haller, Sharon & William Cotterill, Latitude 36 Foods, Mr. & Mrs. Paul Mellon for **Clinton Lucas**; Mr. & Mrs. Goetting, Douglas & Carol Peters for **Larry Roberts**; Kathleen Toelkes for **Donna Pagano**; Meghan Carr, Laurel J. Kiser, Nancy Walker for **Claudia Hubbard Rutkauskas**; Thomas and Elaine Smuczynski for **The Smuczynski Family**; Linda Grady, Susan Karl, Carol Smith, Julie Stebbins for **Tod Teeple.**

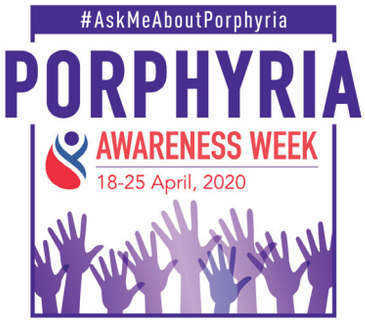
IN HONOR:

Tom McConaugh for **Any Person Suffering**; Richard Buswell for **Robert Buswell**; Candace Colbert for **The APF Staff**; Carole Guadette for **Tristen Gaudette**; Mr. & Mrs. Cartledge, Grayfred Gray, Lori Hanson, Paula Hendrix for **Ralph M. Gray**; Marty Erann for **Eric Lifschitz**; Robert Desnick for **Desiree Lyon**; Mary Ann Koppie for **Robert McGuckin**; Kathleen Toelkes for **Valine Jensen & Linda Peterson**; Mary Mistretta for **Mary Jusko & Margaret Jusko Purcell**; Abby Darrington for **Claire Richmond**; Beverly Roberts for **Lawrence Roberts**; George Rusnak for **Diana Sabella**; Connie & Marin Helleson for **Jennifer Streeter**; George Rusnak Jr. for **George Rusnak Sr.**; Maureen Curran for **Dr. Peter V. Tishler**; Leslie Heineman, Lori Harris, Margie Lewis, Cindy Musoff, Mr. & Mrs. Shah, Beth Tomkiewicz, Sharon & Bruce Wilson for **Jonathan Turell**; Gina Carena, Julie Stebbins, Susan Karl for **Lauren Warren**; Shelley Weinstein for **Sophia Weinstein**; Amy de Court for **Kristen Wheeden;** Iany Schneider & Edrin Williams for **Kristen Wheeden**; Marguerite Baran, Jeanne Blomgren, Kay Cione, Barbara Fahy, Wayne Godsted, Mr. & Mrs. Kent Godsted, Laura Heidy-Halberstein, Virginia Leppart, Eileen Martin, Robert Martwick, Jr., Martha Nickerson, Michael Nudo, Yvonne Patrick, Ellen Ruhmann, Bonnie Schnell, Kristen Starr, Adrienne Young, Diane Young, Greg Young, Susan Young for **Anonymous**.

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.

What's New at the APF
www.porphyriafoundation.com



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

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

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