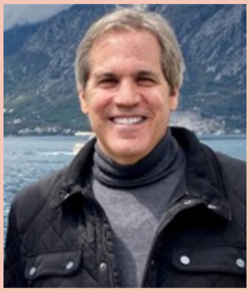
AMERICAN
PORPHYRIA
FOUNDATION

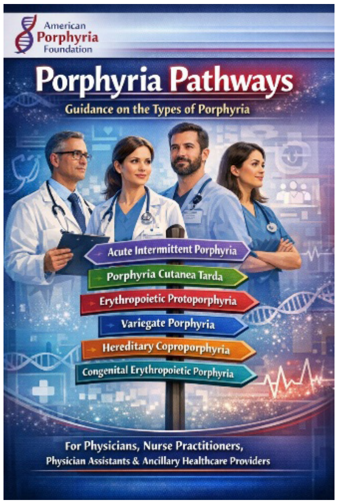
SPRING 2026 **NEWSLETTER**

IN THIS ISSUE

Tom Pletkovich, Our New Executive Director

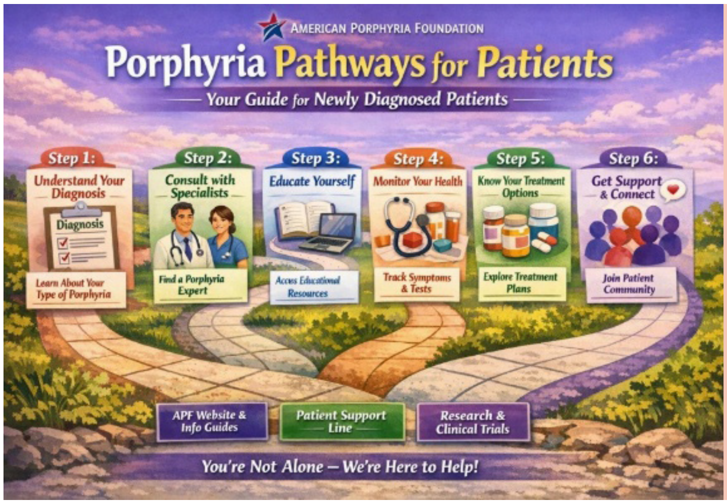


Tom has been instrumental in bringing the organization to new heights in both physician and patient education. He will be leading the implementation of several innovative programs, including Porphyria Pathways for newly diagnosed patients and physicians new to porphyria, Porphyria After Dark, and Shade Squad , a program for EPP kids. Plus He will spearhead a wide range of national global porphyria awareness initiatives, and the expansion of APF's social media presence. With decades of experience in national leadership roles within the rare disease community, Tom has brought valuable expertise to APF. He has been actively engaging with patients, clinical experts, industry partners, and the APF Medical Advisory Board to identify opportunities for continued growth and improvement of the organization. If any of you have suggestions for Tom or would like to send him a Welcome email, see Tom@porphyriafoundation.org.



PORPHYRIA PATHWAYS FOR PHYSICIANS

The APF will be initiating a program to locate and educate new healthcare professionals and provide them with comprehensive educational resources they need to enable them to diagnose and treat each of the porphyrias. If you need a porphyria physician or Healthcare Professional, please contact the APF as we have a database of 6800 doctors who treat the porphyrias. The APF will not only add more physicians, but also Physician Assistants Nurse Practitioners and other ancillary healthcare professionals (HCP).   If you need an HCP for diagnosis and treatment or if you have a doctors who treats you and is willing to treat others, please contact the APF at general@porphyriafoundation.org.



PORPHYRIA PATHWAY

For Patients will be initiated to guide newly diagnosed individuals and families through the overwhelming journey of a porphyria diagnosis by providing personalized support, expert resources, and a clear path forward—from diagnosis to daily management and long-term care.

NEWS

Dr Katharina Schmolly

One of our newest doctors joining the APF team is Dr. Katharina Schmolly, who is based in Los Angeles where she received her medical degree at the David Geffen School of Medicine at UCLA. She writes, I am a first-generation immigrant from Austria. I moved to the US on my own in search of the Great American Adventure. I used to be a horse trainer and British Dressage Instructor and Judge, before joining the US Air Force to become a flight medic. I then got recruited to the University of California David Geffen School of Medicine on a Leaders of Tomorrow scholarship, where I started to become interested in genomic precision medicine and utilizing technology to improve traditional system. I spent a year as a primary care/internal medicine physician on the East Coast before moving back to my Southern California home, where I continue additional training in Genomic Medicine at UCLA while setting up my own practice in genomic precision medicine focusing on longevity, performance and prevention. I see myself as a health consultant who supports the goals of my patients. Outside of work, I enjoy functional fitness after getting injured at CrossFit like so many of us, trail running and hiking in the mountains, kayaking and dog walking. I eat whole, unprocessed foods with an emphasis on high protein and constantly look for ways to reduce environmental toxins in my household, diet and personal care. Dr. Schmolly will be presenting at our upcoming Los Angeles meeting March 19, 2026. Welcome to the APF .

Porphyria After Dark

Is a moonlit social program designed for porphyria people whose best hours begin when everyone else has gone to sleep. Built for porphyria patients who are insomniacs, night-shift souls, creatives, and chronic overthinkers, the program opens in the wee hours—midnight to dawn—when the world is quiet enough to finally hear each other think. Porphyria After Dark isn't therapy and it isn't networking—it's companionship for the sleepless, a place where being awake at the wrong hour finally feels like the right time. Think of it as a living room for the nocturnal: no judgments, no clocks, just people keeping watch together until morning decides what to do with them. Acute porphyria patients are known to have serious sleeping issues. Opening soon, watch the Enews for details to engage in this valuable new program to be held on Discourse.

- Open all night: Drop in at 12:17 a.m. or 4:42 a.m. No schedules, no "too late," no apologies.
- Low-pressure conversation: No small talk mandates. You can talk deeply, quietly, or not at all.
- Shared wakefulness: The comfort comes from knowing everyone else is awake for the same reason—sleep won't come, so connection might.
- Insomnia-friendly topics: Meandering thoughts, half-finished ideas, strange questions, late-night fears, unexpected laughter.
- Gentle atmosphere: Dim light, soft voices, respect for fragile nervous systems and racing minds.

PATIENT MEETINGS

With the great success of the Oklahoma City meeting with Dr. Sanjay Hapani and Patient Leader , Elizabeth Petersen and Richmond meetings with Dr. Bo Zhao and Ginger Davis as the Patient Leader, the APF continues with the following Patient gatherings.

UPCOMING PATIENT MEETINGS

LOS ANGELES, CA will be the site of the March 19 meeting with porphyria expert, Dr. Katharina Schmolly, presenting and answering your questions. We are happy to announce that Dr Schmolly is opening a new Porphyria Center and welcomes patients. Tom Pletkovich, Executive Director of the APF , will host the meeting, thus providing him the opportunity to meet so many of YOU in person. Please bring family and friends and enjoy the camaraderie and time to share about your own porphyria experience.

NEWS

Zooms With Experts

The upcoming Zoom conversations will be featuring DIAGNOSIS AND TREATMENT with Dr. Roy Smith, a leading porphyria expert and hematologist at the University of Pittsburg. EPP, THE SUN AND YOU will be the topic with renowned expert, Dr. Elizabeth Buzney, who serves at Harvard's Brigham and Women's Hospital in Boston. EPP expert, Dr. Tasneem Mohammad from the Henry Ford Hospital in Detroit will also present on EPP. The APF will also host zoom calls in association with some of the Patient meetings which have presentations by experts. Please take advantage of these educational opportunities in the upcoming months and view previous Zoom calls with experts on the APF You Tube channel.

MEMBER STORIES

Carrie Hunter: Everyone with porphyria has a great story to tell of courage, hope, strength and caring for others.

This is why the APF focuses on your stories. The following is the PCT story of Carrie Hunter, who is a strong advocate for PCT and serves on the APF Member Advisory Board. She was diagnosed with genetic PCT at age of 33. Until December 2010, she had no signs of PCT. Soon she began to notice her hands were getting cuts and blisters and were overly sensitive, but she didn't know why and neither did the many doctors she visited, including a dermatologist who ran many tests and biopsies. Still there was no answer. Even after being sent to the Comprehensive Cancer Center, it still took six months and four more doctors to diagnose her correctly. That occurred only after a trip to the Caribbean and a subsequent hospitalization that her diagnosis was discovered and a treatment plan started.

According to Carrie, "From September to December I had a phlebotomy every week to regulate my ferritinand porphyrin numbers. My doctor consults with an expert to help keep my levels normal, especially since I still have major issues with sensitivity to iron and foods. I have made big changes. I don't drink alcohol, eat any meat or iron rich foods or eat things cooked in iron and I avoid the sun. I once heard someone describe it as shadow jumping... and that is exactly what I do." Despite her many ongoing challenges with PCT, Carrie volunteers at the Children's Hospital near her home in Denver. Carrie wants to give back because she says, "I have three beautiful children and I live a fulfilling life. Porphyria Cutanea Tarda has been difficult to adjust to but has not ruined my life!! I am grateful to APF and all the wonderful folks n board and to my APF Facebook friends, who also have made this all easier to deal with--I finally don't feel so alone!"

YOUR STORY IS IMPORTANT, TOO. Contact the APF to share your story. General@porphyriafoundation.org

WHERE: Marriott Courtyard
21101 Ventura Blvd :: Woodland Hills, CA 91364,
Telephone: 818-999-2200

WHEN: March 19, 2026 ~ 6-8 pm

CHICAGO :: The next meeting will be help with expert, Dr. Lisa Boggio as the presenter. Dr. Boggio is well known and beloved by patients in the Chicago area. Tom Pletkovich will also host the Chicago meeting again to meet the people we serve at the APF. You are the center of our world !! Please feel free to bring family and friends.

WHERE: Courtyard by Marriott Oakbrook Terrace
6 Trans AM Plaza Dr. :: Oakbrook Terrace, IL, 60181
Telephone: 630-691-1500

WHEN: April 18, 2026 ~ 2-4pm

HOUSTON :: With Dr. Akshata Moghe will be announced. Thank you to Alnylam Pharma, Recordati RareDisease, and Disc Medicine for sponsoring these meetings. Details on further meetings will be posted here on the Enews .

NEWS

Why Biochemical Tests Are Essential For Diagnosis & Why DNA Testing Is Not Enough

With the increasing availability of genetic testing, it may seem that DNA analysis alone could provide definitive answers. However, in porphyria care, biochemical testing remains indispensable. Accurate diagnosis, appropriate treatment, and patient safety depend on understanding what the body is actually producing and accumulating, not just what genetic variants are present.

Porphyrias Are Functional Metabolic Disorders Porphyrias are defined by the accumulation of specific porphyrins or their precursors in blood, urine, or stool. These biochemical abnormalities are what cause symptoms such as abdominal pain, neurotoxicity, photo-sensitivity, and blistering. DNA testing identifies a potential enzyme defect, but biochemical testing shows whether that defect is functionally active. In other words: **DNA reveals *risk* and Biochemistry reveals *disease activity.*** This distinction is critical because many individuals with porphyria-related mutations never develop symptoms.

Many Mutation Carriers Are Asymptomatic In several porphyrias—especially acute hepatic porphyrias such as AIP -penetrance is low. The majority of people with a pathogenic mutation remain asymptomatic throughout life.

DNA testing alone cannot determine: Whether porphyrin levels are elevated, Whether symptoms are due to porphyria or another condition, and Whether an acute attack is occurring. Biochemical testing, particularly measurement of urinary ALA and porphobilinogen (PBG), is essential to confirm an active acute porphyria.

DNA Testing Cannot Diagnose an Acute Attack In emergency settings, rapid diagnosis is critical. Acute porphyria attacks can be life-threatening and require prompt treatment. DNA results often take weeks. Genetic status does not change during an attack and Elevated ALA and PBG provide immediate diagnostic confirmation. Without biochemical testing, clinicians risk both missed diagnoses and inappropriate treatment.

Porphyria Cutanea Tarda Is Often Acquired Porphyria cutanea tarda (PCT), the most common porphyria, is frequently acquired rather than inherited. Many patients have: . Normal UROD genes, Secondary enzyme inhibition due to iron overload, alcohol, hepatitis C, or estrogen use. In these cases, DNA testing may be normal, but biochemical testing clearly demonstrates elevated uroporphyrins and confirms the diagnosis.

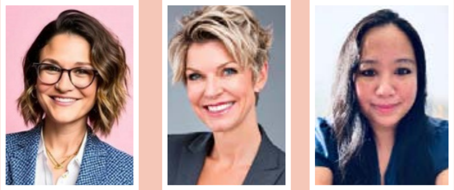
Different Porphyrias Can Share Genetic Findings Some genetic variants are shared across populations or exist as variants of uncertain significance (VUS). DNA testing alone may not distinguish: The specific porphyria subtype and Clinically relevant mutations from benign variants. Biochemical patterns—such as whether porphyrins accumulate in urine, plasma, or stool—are essential for accurate classification.

Monitoring Disease Activity and Treatment Response DNA does not change, but porphyria activity does. Biochemical testing allows clinicians to: Monitor response to treatment (e.g., phlebotomy in PCT), Confirm biochemical remission. Detect relapse early. Assess ongoing risk. This dynamic information cannot be obtained from genetic testing

Guiding Safe Clinical Decisions Many medications, hormones, and metabolic stressors can trigger porphyria attacks. Biochemical confirmation ensures: Avoidance of unnecessary lifelong drug restrictions, Appropriate use of hemin or other targeted therapies. Accurate patient counseling. Misdiagnosis based solely on genetics can cause significant harm, including anxiety, inappropriate treatment, and life-style limitations.

The Complementary Role of DNA Testing This does not diminish the value of DNA testing. Genetic analysis is crucial for: Confirming porphyria subtype after biochemical diagnosis, Identifying asymptomatic carriers, Family screening, Long-term risk counseling. How-ever, DNA testing should complement, not replace, biochemical testing. Thus, Accurate porphyria care requires both tools—used together, in the correct clinical context.

DID YOU KNOW THAT PHARMA HAS PROGRAMS TO HELP PATIENTS ?



Photos, *Barrie, Kim, Lara*

Alnylam Patient Education Liaisons (PELs) are experienced professionals with nursing backgrounds who can offer helpful educational information about AHP They build connections with patients, families, and caregivers through one on one conversations and educational events. PELs can support you with educational information at any point in your AHP journey—whether you're newly diagnosed, learning more about AHP, considering treatment, or already receiving treatment. PELs are employees of Alnylam Pharmaceuticals. They are not healthcare providers and are not part of your medical team. They do not provide medical care or medical advice. All decisions about diagnosis and treatment should always be made by you and your doctor. If you'd like to connect with an Alnylam PEL, you can visit AHPPEL.com.

CUTANEA TARDA

What Is Unusual About Porphyria Cutanea Tarda

Porphyria cutanea tarda (PCT) is the most common form of porphyria, yet it is also one of the most unusual. While porphyrias are typically rare, inherited metabolic disorders that often present early in life, PCT behaves very differently. Its causes, clinical features, diagnostic profile, and treatment distinguish it from other disorders of heme synthesis and make it a unique entity in clinical medicine.

Often Acquired Rather Than Inherited-- Most porphyrias are primarily genetic conditions caused by inherited mutations affecting enzymes of heme biosynthesis. In contrast, the majority of PCT cases are acquired rather than inherited. Although PCT is associated with reduced activity of the enzyme uroporphyrinogen decarboxylase (UROD), many affected individuals do not carry mutations in the UROD gene. Instead, enzyme activity is secondarily inhibited by environmental and metabolic factors such as iron overload, alcohol use, estrogen exposure, hepatitis C infection, or HIV. This reliance on external triggers makes PCT unusual among porphyrias and highlights the interplay between genetic susceptibility and environmental factors.

Late Onset of Disease-- Another distinguishing feature of PCT is its typically late onset. Whereas many porphyrias present in childhood or early adulthood, PCT most often develops in middle age, particularly in individuals with long-standing risk factors. This delayed presentation can contribute to diagnostic delay and prolonged symptoms.

A Purely Cutaneous Porphyria-- PCT is unique in that it causes exclusively cutaneous manifestations without acute neurovisceral attacks. Clinical features include: Fragile skin, Blistering on sun-exposed areas, Scarring and milia, Hyperpigmentation and hypertrichosis, Unlike acute hepatic porphyrias, PCT does not cause abdominal pain, neuropathy, or psychiatric symptoms. This clear separation between skin involvement and neurologic features makes PCT clinically distinct.

Strong Association With Iron Metabolism-- Iron plays a central and unusual role in the pathogenesis of PCT. Excess hepatic iron promotes oxidative stress, which further inhibits UROD activity and leads to porphyrin accumulation. Few other porphyrias are so closely linked to iron metabolism. This relationship explains why phlebotomy—a simple and effective method of iron reduction—is one of the most successful treatments in porphyria care, in contrast to the more complex therapies re-quired for other forms.

One of the Most Treatable Porphyrias-- Unlike many porphyrias that require life-long management, PCT is often reversible. Removal of triggering factors and reduction of iron stores can restore enzyme activity and lead to sustained remission. With appropriate treatment: Skin lesions heal, Porphyrin levels normalize, Patients may remain symptom-free for years, and this degree of reversibility is highly unusual among metabolic disorders.

A Distinctive Biochemical Signature-- PCT has a characteristic biochemical pro-file, marked by significantly elevated uroporphyrins in urine and plasma, with normal or only mildly increased levels of porphyrin precursors such as δ-aminolevulinic acid (ALA) and porphobilinogen (PBG). This pattern clearly distinguishes PCT from acute porphyrias and underscores the importance of biochemical testing for accurate diagnosis.

Association With Liver Disease-- PCT is closely linked to chronic liver disease and carries an increased risk of hepatic complications, including cirrhosis and hepatocellular carcinoma. This strong association with liver pathology is more pronounced in PCT than in other porphyrias, making long-term monitoring essential even after clinical remission.

A Model of Gene–Environment Interaction-- Perhaps most uniquely, PCT serves as a clear model of gene–environment interaction. A partial genetic predisposition combined with environmental and metabolic stressors can disrupt enzyme function and lead to overt disease. As such, PCT provides valuable insight into the mechanisms underlying complex metabolic disorders beyond porphyria itself.

PATIENT ENGAGEMENT

WHEEL OF FORTUNE WINNER VONDA ULFIG WILL BE SHARING HER STORY ON APF PLATFORMS

Wheel of Fortune featured Vonda Ulfig, PhD (left photo), who not only was a big $99,000 winner on the show but also revealed that she spent two months in the hospital with an AIP attack. Despite her illness, Vonda fulfilled her dream of gaining her Doctorate in Business Administration. Please see: Wheel of Fortune Season 43 Episode 105, ("Winter Wonderland") Vonda will be telling her story on the APF platforms soon. Watch the Enews.

Also, DOC, a new popular FOX TV series, highlighted a young woman who was in agony and repeatedly misdiagnosed. Finally, she was diagnosed with AIP after being told that her symptoms were "all in her head." However, she was eventually properly diagnosed on DOC and received life-saving Panhematin infusions, which proved to be both life-changing and critical for her recovery. With porphyria pain. You can view the episode on DOC Series 2 Episode 13.

For more media the APF helped to bring on TV, see https://porphyriafoundation.org/for-patients/media-coverage/

JUSTIN HAMILTON, A LIFE MARKED BY CHALLENGE

Justin Hamilton is a courageous man whose life reflects both the severity of Congenital Erythropoietic Porphyria (CEP) and the re-markable resilience of people living with this ultra-rare condition. His story highlights not only the daily struggles of managing a devastating genetic disorder but also the courage, family love, and advocacy that sustain him every day. Shortly after birth, his caregivers noticed that his urine had a distinctive reddish fluorescence, a classic early sign of porphyrias. At just six months old, after ob-serving blistering of his skin in response to sunlight. Doctors confirmed his CEP diagnosis, which has only a few hundred cases worldwide.

Because CEP causes severe photosensitivity, blistering, and scarring, Justin's daily life has been shaped by careful avoidance of sun-light and managing painful affects of porphyrin accumulation in skin and tissue. Even brief exposure to sun or certain artificial lighting can lead to painful blisters that take weeks to heal and leave permanent scarring. Over time, this repeated damage has affected his skin and vision; Justin has experienced CEP eye complications that took his vision in one eye and severely reduced vision in the other eye requiring ongoing specialist care. In fact, Justin must drive four hours weekly from his home to Denver to keep from losing his remaining eye. Meanwhile, Justin and his wife, Holly, manage chronic sores, blistering, and infections with protective clothing, medications and careful coverage in the light. Despite these challenges, Justin and Holly have built a full and meaningful life with their four children, who are central to their strength and motivation. Justin has spoken openly about painful encounters with strangers who stare or misunderstand his appearance, a common experience for people with rare visible conditions. None-the-less, he emphasizes that his faith, positive attitude, and family support help him navigate both physical and emotional pain. In his reflections, Justin describes CEP bluntly: "CEP sucks" for its hardship and constant care it demands. Yet he also speaks of the lessons it has taught him, including determination, vigilance in self-care, and a deep appreciation for simple joys that many people take for granted. Justin serves on the APF Member Advisory Board, will be participating in the CEP trials. See https://porphyriafoundation.org/for-patients/member-stories/

SHADE SQUAD FOR EPP KIDS

The Shade Squad program for EPP and XLP kids is launching soon! Designed for children in Kindergarten through 4th grade, Shade Squad is packed with fun—featuring colorful cartoons, games, and other exciting activities created just for kids with EPP and XLP. Shade Squad kids even have their own badge. While we're getting ready to launch, families can: Order a free EPP School Guide and sign up for the Shade Squad program. Want a sneak peek at some of the wonderful Shade Squad activities? Check out a sample of the Shade Squad cartoons here :

https://drive.google.com/file/d/1N5NKJ_i1QcT5RavlnDu46xclSZDYyI5t/view?usp=sharing

and

https://drive.google.com/file/d/1sJihrHtQJpRP5y5tny1UmKFiZGSjrbeY/view?usp=sharing

Once you join, you'll receive additional cartoons and EPP and XLP kid activities sent directly to you. With parental consent, EPP kids will also have opportunities to connect with one another online or in person. Knowing other kids with EPP and XLP is incredibly important for a child's emotional health and well-being. Until meeting in person is possible, Shade Squad is the next best thing. Contact general@porphyriafoundation.org

Until meeting in person is possible, Shade Squad is the next best thing.

Great Sadness & Sympathy

In Memory of Larry Lee Stickler

We express our heartfelt sympathy to Paul Stickler, our APF President, and family at the passing of his father, Larry Lee Stickler, 88, of Eden Prairie, Minnesota who died peacefully Dec. 24, 2025. Larry married his high school sweetheart, Jenna Lambert, and was blessed with 71 years together. The couple were beloved in their community. Larry is survived by his wife, Jenna, and daughter Nancy (Rod) Fisher, and son Paul (Carolann) Stickler and grandchildren, Emily, Andrew, Brian, and Grant, and his great-grandchildren, Levi and Olive. We send our sincerest sympathy to Larry's family.

GET READY FOR GLOBAL PORPHYRIA DAY

Held annually on May 18 to raise international awareness, advocacy, and patient organizations worldwide understanding of porphyria.

the APF will join international patient organizations in collaboration with the Global Porphyria Advocacy Coalition to host activities to heighten awareness including wearing purple,sharing porphyria stories, and encourage our members to create their own awareness activities in their communities. Plus, the APF will take part in the worldwide campaign to LIGHT THE SKY PURPLE FOR GLOBAL PORPHYRIA DAY. Kelly Burns, from the Canadian Association, created this amazing program to light landmarks, etc purple for PORPHYRIA. We are not only asking Landmarks but all of you to put a purple light in your window. If photo Niagara Falls can light the world purple, so can you and all the APF members.

The Following people have donated to the APF In Memory of their loved ones. Their families and the APF thank you.

IN MEMORY OF

James DiPerna
Megan Mahoney, Dorothy Burgard, Bill Crawford, Robert Enlow, Larry Glick, Shawn Stringer, Allan Diaz, Martin Lueken, Susan Hart, Gary Millet, Edmund Carney, John & Arlene Kokales, Kristy Walter

Ruthie Loomis
Tanya Harvin, Shelly Flowers, Tanya Harvin, Danielle Ditzler, Eleanor Flowers, Thomas Sondgeroth, Mark Johnson, Brian Clarity, Peggy Harris, Chuck Moore, Bill Rathman, Holly Wagner, Boyce Loomis, Kristen Hartpence, James Fritz, Rita Eastwood, Meagan Capra, Alicia Gassert, Charles Courtney, William Buhrow, Joshua Long, Kenneth Eastburn, Steven Bechtold, Tanya Evanina, `ylie Carroll, Dan Legare, John Nefzger

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Mathew Cole
Dianna Poissant

Sylvester Berdak
Lori Miller

Darlene Bishop
Dianne Fletcher

Sharon Stapleton
Kelly Beach Lovitt

IN HONOR OF

Ralph Grey
Lori Hanson

Desiree Lyon and
Nicole Castellano
Bonie Niglio

Eliza Maria Martinez Uresta
Eliza Uresta

Ginger Davis
Charles Davis

Tasha and Kalel Alicea
Marcia Alicea

DR AKSHATA MOGHE HEADS HOUSTON PORPHYRIA CENTER

For Houston area patients, Dr. Akshata Moghe now heads a PORPHYRIA CENTER IN HOUSTON .

Dr. Moghe is a beloved and renowned porphyria expert who has treated patients with all porphyrias. If you need an appointment, contact the APF to connect you with the Houston Porphyria Center and Dr. Moghe.

DR MOGHE NEEDS PATIENT VOLUNTEERS FOR EPP STUDY

Also note that Dr. Moghe is currently an investigator for the oral inhibitor Portal Therapeutics, Inc. PORT 77 study for Erythropoietic Protoporphyria (EPP). PORT-77 has received FDA Orphan Drug and Fast Track designations. Dr Moghe needs patient volunteers for the study. For more information, contact the APF 866-APF 3635 and general@porphyriafoundation.org

What's New?

Check out **www.PorphyriaFoundation.org**

The information contained on the APF website or newsletter is provided for 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 a consult with personal physician or local treatment center before pursuing any course of treatment.

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Why donate to the APF?

We've put patients first for 40+ years. Staff work nights and weekends helping people worldwide find answers for painful symptoms.

Your donation helps us provide doctor packets for newly diagnosed, add to a growing database of 6,000 treating physicians worldwide, support physician education, and more!

Every donation is tax deductible and incredibly appreciated. The APF does not receive government funding.

Donate on our website 24 hours a day, 7 days a week.

THANK YOU!

NEED TO UPDATE YOUR CONTACT INFORMATION?

Contact 866-APF-3635 or **general@PorphyriaFoundation.org.**

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