

It is our hope one day that all photosensitive porphyria friends will be able to enjoy sun shiny days and beautiful beaches.
RESEARCH IS THE KEY TO OUR CURE !

APF Rarely Discussed Podcast



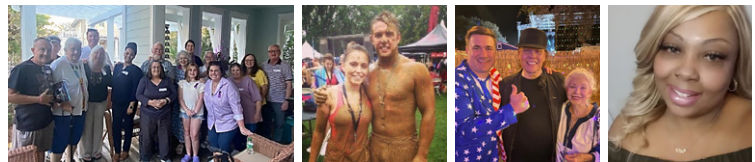
Wheel of Fortune Winner **Vonda Ulfig**, Tic Toc sensation **Ginger Davis**, husband **Charles “Digger” Davis** an F-16 PILOT with 120 combat missions, esteemed porphyria expert, **Dr. Penny Stein** and our own APF Executive Director, **Tom Pletkovich** and many more were guests on the APF Rarely Discussed Podcast. You can watch all these popular podcasts and more at APF website <https://porphyriafoundation.org/podcast/>, Spotify and may other platforms. Join Andrew McManamon bi-monthly and enhance your knowledge of porphyria. THOSE WHO KNOW THE MOST---DO THE BEST. If you would like to be a guest, contact the APF at general@porphyriafoundation.org.

Educational Opportunities

This year, The APF hosted an array of educational opportunities, including in person patient meetings starting in Venice, FL and on to Philadelphia, PA, Oklahoma City, Richmond, Chicago, Pittsburgh, and Santa Rosa Beach, FL. We also provided ZOOM calls for EPP with Dr. Tasneem Mohammad and all porphyrias on a ZOOM with porphyria expert, Dr. Katharina Schmolly. People enjoyed meeting other patients and com-paring their experiences. In fact, they often mentioned that they learned many coping tips from others that they have implemented with great success. Having experts present at the meetings was also an added bonus, especially when they answered questions from the attendees.



A few photos from meetings and awareness efforts. **Left:** Gudrun and George at Philly meeting. **First Row:** Santa Rosa Beach BBQ; Mud wrestling; Pax, James Young Styx APF co-founder and Desiree; Nedra Johnson. **Second Row:** OKC patient meet: Warren, APF treasurer and wife Judith, board member and mental health expert; baby and dog creating awareness. **Third Row:** Shadow Ride; Dr. Bo Zhao, porphyria expert; Ginger Davis with a group from the Richmond meeting. **SRB meeting:** three generations of porphyria people with Desiree, Grandmom Jaimie, Mom Amanda Snow and Ivy, who was the youngest porphyria person at 11 years old and Desiree being the oldest at 79.



Major Printing Problem

Unfortunately, our printer inadvertently left out the entire middle section of our hard copy newsletter that arrives in the mail. So if you thought the APF newsletter was smaller than usual, you were correct. Please read the rest of the newsletter [on the APF website at this link: https://porphyriafoundation.org/apf/assets/file/public/newsletters/26Q1_APFNewsletter.pdf](https://porphyriafoundation.org/apf/assets/file/public/newsletters/26Q1_APFNewsletter.pdf). We are also reprinting a few of the items in this newsletter because of their importance. In fact, you can read years of our newsletters at: <https://porphyriafoundation.org/news-blog/newsletter/>



GLOBAL PORPHYRIA DAY, May 18, 2026

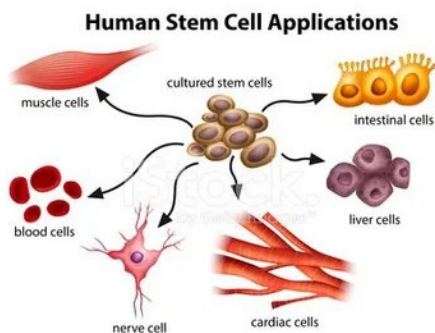


The APF has joined our sister organizations around the world to celebrate GLOBAL PORPHYRIA DAY on May 18, 2026. In the past, the APF hosted Porphyria Awareness Week, however, wanting to collaborate with leaders and patients around the world, the APF joined the GPD opportunity. One of the largest events associated with the GPD is "Light the sky purple" whereby we engaged landmarks to Light their landmark purple and also light the houses of porphyria friends and families. More than



100 families lit their homes with purple lights. Our favorite landmarks were definite-ly the giant Ferris Wheels in Atlanta and San Francisco owned by the Janet and James Cumming family who are not only APF supporters but also Pax Cumming is the APF Patient Care Coordinator. Thanks to Canadian Association for Porphyria and their Vice President, Kelly Burns, for creating this wonderful now annual event. Congratulations to her for gaining 87 landmarks, including Niagara Falls.

CEP: Stem Cell Transplant



A French study has shown that the CEP stem cell transplant eases symptoms in childhood for CEP kids, but complications are frequent study shows. Stem

Cell Transplants or bone marrow transplants can treat children with congenital erythropoietic porphyria (CEP). French researchers found the transplant resolved the symptoms in most of the CEP children, however there were many complications were frequent with half of the children needing a second transplant. Fortunately, those who had the second transplant overwhelmingly had freedom from the severe damaging photosensitivity.

The study, "Hematopoietic stem cell transplantation in pediatric congenital erythropoietic porphyria: a French retrospective multicenter registry study on behalf of the Francophone Society of Bone Marrow Transplantation and Cellular Therapy (SFGM-TC)," was published in the journal *Bone Marrow Transplantation*. Or see <https://www.nature.com/articles/s41409-026-02824-1>

Shirley Schlag – The Ultimate Advocate

Most people start slowing down their advocacy efforts at 76 years old but NOT Shirley Schlag. Shirley put on her purple clothes and set out to tell her community and the communities around her about porphyria. She brought educational materials to many doctors' offices and clinics and told the staff all about porphyria. Shirley has been doing this for many years. In the past, the APF hosted PORPHYRIA AWARENESS WEEK in April each year. We now, however, have joined our sister organizations around the world to celebrate GLOBLA PORHYRIA DAY to help unite us all world-wide.

To date, Shirley begins her advocacy efforts for the APF from the April time frame until Global Porphyria Day and beyond.



We are proud of her and ask that each of you use Shirley as an example. Tell your community and your medical professionals about porphyria. Call your media stations to get on a program or be in the newspaper.

TELL YOUR STORY EVERYWHERE. THANK YOU, SHIRLEY

MEMBER STORIES

April Trebelhorn: Nurse Practitioner (NP), Living Without Fear: My Journey with AIP

I grew up always knowing there was a family history of acute intermittent porphyria (AIP). But beyond that, it wasn't something I truly understood. I had surgeries, my wisdom teeth removal and tonsillectomy, and simply mentioned my family history to the anesthesia team. That was the extent of my awareness.



My first porphyria attack came unexpectedly at age 28. At the time, my young son had been admitted to Children's Hospital for four days. During his hospitalization, he was unable to eat, and as parents staying by his side, we also weren't eating much. My intake significantly decreased. At the same time, I had just found out I was pregnant with my daughter. A few days into my son's hospital stay, I began experiencing lower back pain. I initially brushed it off, assuming it was from sleeping on the uncomfortable sleeper sofa. But after my son was discharged, things quickly worsened.

By Friday, I was experiencing severe abdominal pain, nausea and vomiting. I could barely eat and struggled to take care of my child, let alone myself. I went in for evaluation, where an ectopic pregnancy was ruled out. Labs were drawn, and I was told to increase fluids. I was discharged with reassurance and given pain medications considered safe in early pregnancy. By Saturday morning, I still wasn't improving. My primary care provider had me come in for IV fluids and pain control. For a short time, it helped. I was also told constipation could be contributing to my symptoms. But that night, everything escalated. The pain became unbearable unlike anything I had ever experienced. My husband rushed me to the emergency department. I

arrived hyperventilating, unable to speak clearly, and completely consumed by the intensity of the pain. In the ER, I received IV fluids and multiple doses of pain medication before I could even begin to process what was happening. Then, something pivotal occurred.

The emergency physician, Dr. Petersen, who I am forever grateful for, noticed my family history of porphyria in my chart and asked, "Do you have porphyria? Have you ever had an attack before?" I hadn't. At the time, I didn't fully understand what an attack would look like. But he recognized the possibility and sent my urine off for testing. I was admitted to the hospital, where I remained for 10 days on a continuous IV pain pump for pain control. I went through countless tests, labs, imaging, everything, yet there was no clear diagnosis to explain my symptoms. A week later my urine porphobilinogen (PBG) test came back, and my levels were through the roof. I was treated with Panhematin, and by the third dose, I began to feel relief. Panhematin treatment ultimately saved my life. After discharge, I returned the following day to complete my final infusion. My symptoms gradually resolved, but it took about a month to fully regain my strength. The attack had completely taken everything out of me. Despite everything, I went on to have a normal pregnancy, and my daughter was born healthy with no complications.

Following my hospitalization, I was referred for genetic testing and was found to carry the HMBS gene mutation. This diagnosis led to additional testing within my family. We discovered that my grandfather, mother, sister, and I all have the mutation, and now, both my sister and I each have daughters who also carry the mutation for acute intermittent porphyria. In our family, it has been predominantly expressed in females.

I was fortunate to connect with specialists, including renowned porphyria

experts, Dr. Pierach and Dr. Vercellotti at the University of Minnesota. They provided invaluable education and guidance on how to live with acute intermittent porphyria. One piece of advice from Dr. Pierach has stayed with me ever since: "Live your life like you don't have the disease. Don't let it control you." I held onto that.

For six years, I did not experience another attack. Then, I went through a difficult period where I was hospitalized three times within one year. At that point, it became clear I needed a different approach. I wasn't entirely sure what my triggers were, fasting, hormonal changes, stress, but I knew something had to change. I started Civlaari injections and stayed on them for about a year before eventually stopping due to side effects. Fortunately, during my time on Civlaari, I was able to avoid hospitalizations and manage flare ups with IV dextrose and increased carbohydrate intake. Since then, I have had one flare requiring a course of Panhematin infusions. Otherwise, I consider myself very fortunate. I was diagnosed during my first emergency room visit, something I know is rare. It truly hurts my heart knowing that so many people struggle for years with symptoms before finally receiving a diagnosis.

Today, I have a treatment plan in place. My local hospital keeps Panhematin readily available, and I work closely with Dr. Vercellotti at the University of Minnesota, while also receiving care through my small-town clinic, Glencoe Regional Health, where I work alongside the same team that cares for me. I am incredibly grateful for providers who listen, take my symptoms seriously, and act quickly to get me the medication I need to control my porphyria. I've learned how to manage my condition day-to-day, prioritizing nutrition, avoiding prolonged fasting, managing stress, and stabilizing hormonal fluctuations. I stay active and listen closely to my body. But

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more than anything, this journey has given me purpose.

At this stage in my life, I feel called to be an advocate, not only for myself, but for others. Having a daughter and a niece with porphyria has changed everything. I feel a deep responsibility to educate others about acute intermittent porphyria, how to recognize it, how to diagnose it, and most importantly, how to listen to patients and treat their symptoms appropriately.

Because unless you've experienced it, you cannot fully understand the severity of the pain during an attack.

There was a time when fear consumed me, fear that the pain would return, fear that I might not be able to live a normal life, fear that no one would listen or believe me when I needed help the most. But through that fear, I found my

voice. I have learned to advocate for myself, and now, for the next generation in my family. That is why I chose to become involved with the American Porphyria Foundation. Being part of a community of individuals who understand this journey has been incredibly humbling. It reminds me that I am not alone, and neither are they.

Editor's note. We are happy to announce that April, who is a Nurse Practitioner, will be treating patients with the acute porphyrias. If you live near April and need assistance and a referral, please contact the APF for help.

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

Patient and Doctor Packets



Did you know the APF sent out over 4000 educational packets last year. These comprehensive packets for each type of porphyria have been a key force to increase proper diagnosis in all the porphyrias. The packets include a diagnostic primer, forms, information on treatments and even forms for free DNA for acute porphyrias. Since porphyrias are rare and most healthcare professionals have never seen a porphyria patient, the step-by-step instructions for diagnosis and treatment are essential for a patient to be diagnosed and treated. Please contact the APF at

general@porphyriaofundaiton.org or 866 APF.3635 for your free packets



Samantha Oviawe, APF SOCIAL MEDIA DIRECTOR, brings a unique blend of creativity, digital strategy, and technical expertise to the American Porphyria Foundation. With a background in social media, digital media, UI/UX design, web development, healthcare marketing, and mission-driven digital storytelling, Samantha has built her career around making important information easier to understand,

SAMANTHA OVIawe: APF SOCIAL MEDIA DIRECTOR

more accessible, and more meaningful for the communities who need it most.

As APF's Social Media Director, Samantha is passionate about using digital platforms to help patients and families feel less alone. She is excited to help expand awareness, strengthen APF's online presence, and create content that connects patients, caregivers, physicians, and advocates through education, storytelling, and shared understanding. Samantha's technical expertise is extraordinary but her kindness and compassion for patients is tantamount.

Samantha is honored to be part of APF's mission and looks forward

to helping amplify patient voices, promote life-changing resources, and build a stronger online community rooted in hope, compassion, and support for everyone impacted by porphyria. The entire team at the APF is thrilled to have Samantha as a new TEAM APF member.

Samantha will be working on our new APF website. If you have any suggestions you would like to see implemented, please contact Samantha@porphyriafoundation.org or call the APF. We sincerely thank DEBRA KNAPP for heading the position while we searched for a permanent Director. Debra will continue to assist and guide with our social media platforms.

Did You Know APF's Path Forward in 2026 - Year of Action, Advocacy, and Hope



- The APF distributed 4000 doctor packets one on one.
- The APF educated over 3000 doctors
- The APF has a database of over 6000 doctors who treat porphyria
- The APF website had 110 000 visitors in 190 countries.
- The APF has a membership of almost 20,000 people in 120 countries.
- The APF Enews is read by over 17, 000 people.
- The APF maintains a 24/7 Hotline to help YOU.
- The APF reels have reached up to 40 ,000 viewers.
- The APF created THE porphyria pathways program to help newly diagnosed patients.
- The APF expanded the PORPHYRIA PARTNERS program to engage patients who need a shoulder to lean on with patients who are willing to be supportive.
- The APF assisted over 6000 people who contacted the APF for help with porphyria.
- The APF had podcast guests from patients to the most esteemed physicians in the world.
- The APF joined the Global Porphyria Day with sister organizations around the world.
- The APF assisted the Pakistan Porphyria Foundation to implement their website and assisted other international patient groups
- The APF is developing a program to assist our members with insurance denials and social security denials
- The APF created the SHADE SQUAD EPP School Guide
- The APF maintains a service for patients to discuss even the most private questions.
- The APF hosted nine patient meetings and numerous ZOOM calls with experts.
- The APF maintained eight Facebook groups.
- The APF maintained an Instagram account updating our members frequently
- The APF hosts a Book Club and Crafters Club to enjoy activities together other than just porphyria related projects.
- The APF helps create small group gatherings in communities with few patients to enable one on one communication.
- The APF received generous donations from industry, patient donors, family and friends

AND SO MUCH MORE...

YOUR DONATIONS MAKE IT POSSIBLE FOR THE APF TO ACCOMPLISH ALL THESE LIFE CHANGING ASSISTANCE PROGRAMS. YOUR DONATION IS NEEDED. PLEASE DONATE HERE:

PATIENT ENGAGEMENT



GLOBAL PORPHYRIA
ADVOCACY COALITION



Safe/Unsafe Drug List In Spanish---Versión En Español De La Base De Datos Napos

We are excited to announce the launch of the NAPOS database of safe and unsafe drugs for acute porphyrias, now with full Spanish translation. Safety doesn't have a language barrier anymore. For all our Spanish-speaking patients and doctors, you can now check the safety of any medication instantly from your phone. A huge thank to Ipnet, Global Porphyria Advocacy Coalition, and the NAPOS team for their incredible work on this translation!

The translation of the NAPOS database represents a critical milestone in our mission to guarantee patient safety on a global scale. To maximize the impact of this resource, we urge all member associations to review the attached "Call to Action" document. It contains the strategic guidelines and official materials needed to effectively promote this tool within your medical and patient communities. Your collaboration is essential to establishing this safety standard throughout the Spanish-speaking world!

¡Hoy, 18 de mayo, el mundo se viste de púrpura para crear conciencia sobre la comunidad de Porfiria! En todo el mundo, los monumentos se iluminan para recordarnos que somos una red global fuerte e informada.

Pero no solo nos estamos iluminando; *estamos actuando.*

Nos emociona anunciar que la **VERSIÓN EN ESPAÑOL DE LA BASE DE DATOS NAPOS** ha sido lanzada oficialmente. La seguridad médica ya no tiene barreras de idioma. Para todos nuestros pacientes y médicos de habla hispana, ahora pueden verificar la seguridad de cualquier medicamento instantáneamente desde su teléfono. ¡Un enorme agradecimiento a Ipnet y al equipo de Napos por su increíble trabajo en esta traducción!

<https://www.gpac-porphyria.org/napos>

CHEERS AND TEARS

We are a community who cares about each other. Claire Richmond, who had AIP, is recovering from a Liver Trans-plant and is recovering well in Omaha, Nebraska. Claire is one of our Member Advisory Board/MAB members and has assisted the APF in creating our newsletters. Mike Kenworthy, who also is a MAB member, is recovering from a serious heart attack in Miami. Mike, who has XLP, has been an advocate for the APF and research patients for over twenty years. We pray for a speedy and full recovery for Claire and Mike.

FDA Committee and Patient Perspective Submission to the FDA – EPP/XLP – Bitopertin to the FDA



After the FDA denied Bitopertin approval as a treatment for EPP, the APF developed a strategy to help mitigate the situation. Knowing an assault tactic would not be appreciated by the FDA, the APF gathered a committee of people on Bitopertin and began to develop a plan to impact the FDA positively. We engaged (photos r to l) Steve Ferry, George Ragsdale, Pierre Mouledoux and Jim Bowie, to assist in the development of the strategy and the APF response to the FDA. Reaching out to the FDA rare disease representatives and even a former commissioner greatly assisted us in reaching the FDA in a positive way. The FDA responded favorably to our efforts and APF suggestions, like expanded access. We are proud to have collaborated with the FDA committee, the FDA to provide the letter linked and the expanded access suggestion. See the letter sent to the FDA on behalf of the APF and the APF FDA committee by our Executive Director, Tom Pletkovich: <https://porphyriafoundation.org/news-blog/all-news/apf-fda-committee-and-patient-perspective-submission-to-the-fda-re-bitopertin-for-epp-xlp/>

Unable To Find A Diagnosis---There Is Hope



Recently, the APF hosted a ZOOM call with porphyria expert and APF Scientific Advisory Board member, Dr. Katharina Schmolly. After a swell of requests for the ZOOM recording, the APF is responding by creating a link to enable all of you to view this outstanding presentation and hour

of answering questions. VIEW THE ZOOM CALL HERE: <https://drive.google.com/file/d/17m9iIHoztMEwhgZxyf4FAfXhY-hlekYYz/view>

Dr. Schmolly and colleagues recently received a sizable grant from National Science Foundation Small Business Innovations



zebraMD

Research Grant to enhance their new platform and app, **zebraMD**. The

National Science Foundation grants are given to transform scientific discovery into products and services with commercial and societal impact.

At **zebraMD**, Dr Schmolly and her colleagues are building Electronic Health Record (EHR) integrated clinical decision support tools for physicians at the point of care to improve the diagnosis and care of people with rare and genetic diseases. The team is a group of academic physicians and health tech entrepreneurs wanting to solve the problem of under-recognition of rare diseases, like porphyrias, particularly in the community and under-resourced settings, and help bring the standard of care to any clinic, hospital, physician in the world. No need to wait for a specialist referral!

Their tools use patient records automatically via EHR connection or via pdf upload/text input/wearable apps and devices, anything they have, along with existing published scientific literature, research, guidelines, to help identify undiagnosed patients and help identify care gaps in already diagnosed patients. Their system then displays a message to the treating provider informing them their patient may have an undiagnosed rare disease and

Continued on next page.

BITOPERTIN EXPANDED ACCESS LAUNCH NOTICE

disc)medicine

After collaborating with the FDA representatives and the APF-FDA committee, the APF is proud to announce that Disc Medicine has achieved an FDA expanded access program for Bitopertin. Thank you to our committee and all who were involved in the process. Please see the announcement: <https://ir.discmedicine.com/news-releases/news-release-details/disc-medicine-launches-expanded-access-program-bitopertin-epp>

If you are interested in the EXPANDED ACCESS PROGRAM, please contact the APF at 866-APF 3635 or general@porphyriafoundation.org.

what to do next, or, if already diagnosed, it supplies the summarized most current treatment recommendations and alternatives if there are uncontrolled symptoms still, matching clinical trials, patient support groups and next steps for the patient. They are currently pilot testing **zebraMD** at UCSF in San Francisco and Weill Cornell in New York for 10 initial rare diseases We are grateful that Acute Hepatic Porphyrias is among them!

Because of inquiries from our rare disease patient world, they are now also developing a patient app/platform, where any individual can make an account, connect all their medical records and use their algorithms for free. Their platform is HIPAA compliant, and they do not sell data. You can choose to opt in to be contacted for research purposes, for example, if they find matching clinical trials, you would be a candidate for, you can choose to

opt in to be contacted by other patients with similar conditions, and you can choose to opt in for paid research opportunities, where the patient then gets paid for participating in certain academic studies.

The APF maintains a PATIENT FIRST ideology and are pleased that the ethos of the team is that patients should benefit from their own data. It is also important to us that **zebraMD** will enable people to help each other. The platform will make science and AI directly clinically relevant and actionable. Plus, the program will provide people with the tools to improve their lives rather than having to wait on specialist referrals and being dependent on the physicians opinions. The platform and app are and will always be free physicians and patients. Thank you Dr. Schmolly and all involved in **zebraMD**.

The APF is grateful to all who donated IN HONOR AND MEMORY of our beloved members. We sincerely thank you

IN MEMORY OF

WILLIAM HEPP

Martin Russo, Tina Muldoon, Karen Resko Matt, John and Darlene Anderson, Kara Rufo, Anne Gallagher, Eileen Wilderman, Michele Huges, and John Grande donated a gift to the APF in William's memory

RUTHIE LOOMIS

these friends and family donated to the APF in her memory. Shannon LeGrice, Alice Cassert, Charles Courtney, Elanor Flowers, shelly Flowers, Dan-ielle Ditle, Kylie Carrol, Mark Johnson, Boyce Loomis, James Fritz, Kristen Hartpence, Peggy Harris, William Buhrow, Joshua Long, Kenneth Eastburn, Bill Rathman, Dan Legare, John Netfzger, Holly Wagner, Brian Clarity, Steven Bechtold, Tanya, Evanina, Meagan Capra, Chuck Moore, Ginni Guiton, Rita, Eastwood, Tanya Harvin, Tom Sundgaroth

SUSAN YOUNG

Stretch Ledford, Desiree Lyon, and Jeffery Ravitz lovingly donated to the APF in memory of Susie Young. Susie's husband, JY young was co-founder of the APF and remains on the board to date.

SHARON STAPLETON

Kelly Beach Lovett kindly donated to the APF in memory Sharon's memory

SANDRA HORN

Gary Horn donated in Sandra's memory.

DR PETER TISHLER

Maureen Curran donated in Dr. Tishlers memory for the many years he devoted to porphyria patients.

KAREN HALTERMAN

Jeffery Halterman donated in Karen's memory

JAMES DIPERNA

Joe and Shannon Carney, John and Arlene Kokales, Kristy Walter Megan Mahony, Dorothy Burgard, Martin Lueken, Robert Enlow, Larry Glick, Susan Hart made a gift to the APF in James' memory

CAROL AND KARL RUSNAK

George Rusnak kindly donated in their memory.

ANN HOLQUIST

given by Megan Rockey in memory

ANNA MARIE MEYERHOFF

lovingly given by Gudrun Debes

AMY ROSE BURKE

donated to the APF in memory by James Bowie, Desiree Lyon, Nicole Castellano and Gregory Taunton.

DARLENE BISHOP

given by Dianne Fletcher in her memory

DONNA PAGANO

given in memory by Kathleen Toelkes

ELIAS VARVARENIS

donated in her memory by Alexandra Varvarenis

ELLANE HEFLIN

by her children Desiree, Joseph, Deborah, Elizabeth, April

MATTHEW COLE

Dianna Poissant in her memory

IN HONOR Gifts were also donated to the APF IN HONOR of family and friends. We sincerely thank all of you for your generosity and kindness.

IN HONOR OF

TASHA AND KALEL ALECIA

by Marcia Alecia

NICOLE CASTELANNO AND DESIREE LYON

by Bonie Niglio

RALPH GRAY

by Lori Hansen

MELISSA NEGIN

by Andrea and Richard Kringstein, Robin Kaplan, Carmen and Ken Reno, Diane Rocchio-Cohen, Karen and Eric Ginsburg.

MEGHAN MONVILLE

by Lori Monville

JOE KELLY

by Joseph Kelly

GINGER DAVIS

by Charles Davis

ELIZA MARIA MARTINEZ URESTA

by Eliza Uresta

ADAM CAFASSO

by Carolyn Cafasso

DAVID WELCH

by Bettye Welch

In Memory
In Honor



APF

What's New?

Check out www.PorphyrriaFoundation.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.



NEED TO UPDATE YOUR CONTACT INFORMATION?

Contact 866-APF-3635 or
general@PorphyrriaFoundation.org.

Your donations make it possible for the APF to accomplish all these life changing assistance programs. Your donation is needed. Please Donate here: <https://porphyrriafoundation.Org/get-involved/donate/>

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