AMERICAN
PORPHYRIA
FOUNDATION

SPRING 2025 **NEWSLETTER**

IN THIS ISSUE

2024 PRESIDENTIAL AWARD WINNERS

Each year, the American Porphyria Foundation proudly honors extraordinary individuals whose dedication has significantly enhanced porphyria awareness and deepened support for those living with this rare condition. For 2024, we are thrilled to celebrate the remarkable achievements of patients and advocates Gudrun De-bes, PhD Claire Richmond, Mayra Martinez, and Pax Cumming.

Dr. Gudrun Debes is an esteemed immunology researcher whose compassionate approach extends far beyond the laboratory. Known for her relentless commitment to patient care, she offers a comforting hand to those in need while meticulously tracking groundbreaking research and significant advancements in porphyria science across the globe. Working closely with the APF, she not only inspires hope but also empowers pa-tients with the latest information and resources. Dr Debes serves on the APF Member Advisory Board.

Pax Cumming is a familiar and much-loved figure among APF members. In his role as the APF Patient Care Coordinator, Pax diligently shares critical information about porphyria to both patients and healthcare professionals, ensuring that accurate knowledge is widely disseminated. His commitment goes well beyond typical job responsibilities; Pax is a steadfast advocate for patients worldwide, listening to their unique needs and providing compassionate support. He has forged meaningful connections, offering comfort and friendship to those who are suffering just when they need it most.

Claire Richmond is a talented author whose work beautifully intertwines her personal journey with porphyria and her exceptional writing skills. Through her vivid storytelling, Claire recounts the trials and tribulations of living with numerous debilitating attacks. Her insightful articles provide invaluable coping strategies for fellow patients, turning her experiences into a beacon of support for those navigating the complexities of this condition. Claire serves on the APF Member Advisory Board and designs and writes columns for the APF newsletter.

Mayra Martinez is a courageous individual who has bravely shared her harrowing experiences with persistent, severe attacks and the paralysis that followed. Her heartfelt accounts of struggle and resilience resonate deeply with others facing similar challenges. Moreover, Mayra has utilized the power of social media, creating impactful video reels that offer encouragement and guidance to fellow patients, helping them feel less isolated in their journeys.

We extend our heartfelt gratitude to each of our award recipients for their remarkable contributions and unwavering commitment to the porphyria community!

EPPer Aaron Pudlicki Takes On New Zealand's Te Araroas Trail

Sandy Pudlicki, Aaron's mom, writes, "Since the age of six, Aaron Pudlicki has been challenged by EPP, but he has not allowed it to define him. As an avid backpacker, Aaron has hiked many of the National Parks in the U.S. On December 13th, he received his master's degree in Forest Resources from the University of Georgia. To celebrate his graduation, On January 4th, he began a new challenge. He will be "tramping" The Araroa ("The Long Pathway") in New Zealand. The Araroa trail is about 3,000 km. (1,900 miles) long and goes from one end of the country to the other, passing through beaches, mountains, rivers, towns, cities and countryside. The trail has approximately three hundred sections and generally takes through-hikers three to six months to complete the trek. Aaron is planning to complete it in 4 months!"

We wish Aaron much success on his trek and future endeavors and congratulate him on earning his master's degree. We also thank the Pudlicki family for being such supportive members since 1996, when their oldest son, Daniel, was diagnosed with EPP. Sadly, we honor the memory of Daniel, who was struck down by a drunk driver at the age of twenty-three on June 8, 2015.

The APF Exhibits At AASLD And ASH

The APF exhibits at targeted medical conventions annually to enhance porphyria education and awareness. Plus, APF Director, Nicole Castellano, had the opportunity to meet with experts like, Dr. Bruce Wang. We exhibited at The American Association for the Study of Liver Disease (AASLD), which is the leading organization of scientists and healthcare professionals committed to preventing and curing liver diseases. They foster research that leads to improved treatment options for millions of liver disease patients and advance the science and practice of hepatology through educational conferences, training programs, professional publications, and partnerships with government agencies and sister societies. Their convention, called THE LIVER MEETING, is held annually and attended by thousands of medical professionals around the world.

The APF also exhibited at the American Society of Hematology (ASH) meeting, which is the world's largest professional society of clinicians and scientists who are dedicated to conquering blood diseases. Since 1958, the Society has led the development of hematology as a discipline by promoting research, patient care, education, training, and advocacy in hematology. The ASH convention is the world's most comprehensive hema-tology event.

By becoming an exhibitor at both conventions, the APF showcases our educational materials and services to advance the education and awareness of porphyria. Nicole and the APF team engaged with leaders in the national and global disease communities. Next year's liver meeting will be held in Washington, DC, Nov. 7-11, and the ASH meeting will be hosted in Orlando, FL, December 6-9. If you live near the convention sites and are interested in volunteering at the APF exhibit booth, please let us know. It is a fantastic opportunity to meet doctors, nurses and other medical professionals and share your porphyria experience, as well as meet other porphyria people like Sheryl and Moriah McLellan, who stopped by our exhibit booth to greet Nicole.

YOU ARE NEEDED TO HELP VOLUNTEER AT THE APF EXHIBIT BOOTHS AT UPCOMING MEDICAL CONVENTIONS IN YOUR AREA. WATCH YOUR ENEWS FOR DETAILS.

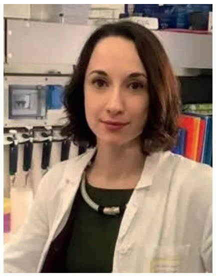
New Scientific Advisory Board Members

The APF welcomes two new SAB members, Jasmin Barman-Aksözen, PhD from Switzerland and Francesca Granata, from Italy. Both scientists are highly regarded researchers and extraordinary EPP advocates.

Dr Barman's main research interest is the drug development for rare diseases, which covers the entire life circle of a drug, i.e., basic research, trial design, approval and benefit assessment/access with primary expertise in the porphyrias. She works as a postdoctoral scientific associate at the University of Zurich/ Children's Hospital and the Municipal Hospital in Zurich, the Swiss Reference Center for Porphyrias. Dr. Barman is also a senior lecturer at the University of Zurich and a guest lecturer at the University of Applied Sciences Zurich. Together with a group of dedicated patient advocates, Dr. Barman co-founded the International Porphyria Patient Network (IPPN) to provide support and counseling for porphyria patients. She also collaborates with national and international patient associations in scientific, medical, and healthcare policy matters and has been featured widely in all forms of media speaking on EPP.

Dr. Barman suffered from severe photosensitivity all her life with no answers. Then at age 27, while at university, she related, "I found this new Wikipedia article named 'erythropoietic protoporphyria' and thought: Wow, this is the description of my life." Indeed, she had EPP! Thus began an amazing career of research and advocacy.

https://porphyriafoundation.org/for-patients/member-stories/erythropoietic-protoporphyria-and-x-linked-protoporphyria/jasmin-barman/ and another amazing in depth interview with Dr. Barman https://nccr-rna-and-disease.ch/news/no-16/interview-jasmin-barman



Dr. Francesca Granata hails from Italy and discovered the name of her disease, erythropoietic protoporphyria (EPP), during a biochemistry lesson in 2008 while she was at university studying biology. Before that time, she says, "I had lived for 23 years trapped inside two different types of shadows: a physical shadow and a mental one. The first was due to my condition; in fact, the symptoms of EPP, triggered by exposure to light, include burning sensations, acute skin pain, itching, edema and skin lesions, which led me to live without the sun. The second shadow was due to my inability to find an answer and the difficulty of explaining the limitations of my life without a diagnosis."

Continued on next page.

ADVOCACY

After that defining moment, she began working at the Porphyria Center of Fondazione IRCCS Cà Granda Ospedale Maggiore Policlinico di Milano, to improve her knowledge about EPP working with porphyria experts Dr. Maria Cappellini and Elena Di Pierro. She helped achieve many goals internationally by meeting with competent authorities, working on the dissemination of information and patient empowerment. In Italy, Granata continued with her research activity through the publication of scientific articles in peer-reviewed journals and in the mainstream Italian media, raising considerable interest and support, including initiating the Vivi Porfiria organization. Her amazing Ted Talk can be viewed.

Publications by Drs Barman and Granata: Quality-Adjusted Life Years in Erythropoietic Protoporphyria and Other Rare Diseases: A Patient-Initiated EQ-5D Feasibility Study *https://www.mdpi.com/1660-4601/20/7/5296*

Heme Biosynthetic Gene Expression Analysis With dPCR in Erythropoietic Protoporphyria Patients *https://sciprofiles.com/publication/view/705780b87eeac1da141fba8c428d0fdc*

Both scientists are renowned in the field and are involved in the National Institute for Health and Care Excellence (NICE) to help bring the afamelanotide/Scenesse treatment for EPP to England as they have done for Italy, Germany and Switzerland.

MEMBER STORIES

Building Porphyria Community

One of the main goals of the APF is to foster a sense of community among porphyria patients and their families. One of our programs to accomplish this important goal is our PORPHYRIA PARTNERS PROGRAM (PPP), whereby the APF connects patients with the same type of porphyria. Patients share coping tips, their triumphs, sadness, and all the challenges of a rare illness. Through the PPP and the APF's social media sites, new friendships are formed every day If you would like to join the PPP, please contact the APF. The following is a poignant, heartwarming story of the PPP porphyria community at work.

l-r Kalel Alicea, Mayra, Tasha

Tasha Alicea, a dedicated moderator in our APF Facebook groups and APF Member Advisory Board participant, shares an inspiring story about how fellow PPP partners, Pastor Wilson Martinez and his wife, Mayra, became her unexpected source of support during a difficult time. When Tasha's brother, Alann Lee (AJ) Green, was tragically murdered, her family was heartbroken and struggling to arrange his funeral. Tasha recounts, "I faced numerous roadblocks while trying to plan my brother's service. With the holidays approaching, the challenge became even more daunting. Some churches informed me that I could not hold a service for him because he was not a member, including my own church. It was incredibly frustrating. I encountered many high fees that simply exceeded our budget. After finally securing a church, they later presented additional costs that had not been discussed, forcing me to cancel as it was beyond our means. I was desperate, with only ten days left, praying and pleading with God for guidance and assistance.

Pastor Wilson Martinez

Then, I remembered Mayra, a fellow porphyria sister who lived in California. In one of our past discussions, she had mentioned that she and her husband, Wilson, had a church where he served as the pastor. I reached out to her, and to my relief, she responded immediately. Without any hesitation, Mayra and Wilson offered their church and their support. Initially, I was not certain of the church's location, only knowing it was somewhere in Southern California. I had no idea just how fortunate I was when they shared the address, and it was only minutes away from my family's home. It felt like a Divine intervention, a true tender mercy from God. They handled everything and made the process incredibly easy for me. It is hard to express how grateful I am for their kindness, love, and unwavering support. Our journey began through our shared experiences with porphyria, but it has grown into a meaningful friendship, strengthened by some of life's most challenging hardships." If you have a story about community building or finding a porphyria friend in your area, please contact the APF!!!

Acute Porphyria Safe-Unsafe Drug Database

The newest version of the Safe / Unsafe drug database can be accessed on the APF website, www.porphyriafoundation.org. The information provided in this database is intended for use by healthcare professionals as guidance for their treatment of patients with an acute porphyria or in persons with a genetic disposition for acute porphyria. The Drug Database for Acute Porphyrias was created and established at the Norwegian Porphyria Centre (NAPOS), Haukeland University Hospital, Norway, in 2002 through the visionary work of Dr. Atle Brun, who for 20 years was the driving force behind the drug database. The database expanded in 2005 from being only a Nordic database to an international online resource and has been further updated over the past years by a collaboration of experts.

As part of an EU-funded IPNET project, clinical drug reports were collected, which contributed to strengthening the evidence of the safety classification of many drugs and verifying the classification method. Currently, NAPOS regularly updates the database with the support of pharmacists and porphyria specialists from the UK Porphyria Medicines Service (UKPMIS), Cardiff Porphyria Service, and the Ipnet Safety of Drugs for Porphyria Patients Working Group (WG-DRUGS).

The Norwegian Porphyria Centre (NAPOS) developed, updated and oversees the drug list. In the NAPOS drug list, drugs are classified into different risk categories based on a thorough evaluation of international clinical experience, published case reports, and theoretical considerations. It is important to be aware that this list involves some degree of uncertainty. While it may be of interest to patients, decisions regarding drug use in acute porphyria should always be made in consultation with healthcare professionals.

We gratefully acknowledge the large contributions of Professor Stig Thunell from Porfyricentrum, Karolinska University Hospital, Sweden, for his work in both method development and drug evaluations. We are grateful for the contributions of all those who participated in this IPNET project and for those who submitted clinical drug reports to help develop the NAPO drug database. If you have an acute hepatic porphyria (AHP) and suffered an attack due to a new or unclassified drug, please contact the APF. 1-866-APF-3635 and share your experience. We will then report your experience to researchers.

Treatment Assistance Programs

Healthwell Assistance Program - At the ASH convention, Nicole also met with Michael King from the Healthwell Foundation. We are most grateful to Healthwell for providing a porphyria assistance fund of up to $4,000 a year for copay premiums and Pharmacy Card Fund assistance. For more information on this financially helpful program for patients, please see Healthwellfoundation.com or contact the APF at 866-APF-3635.

Alnylam Assist - Alnylam Assist® provides patient support services for you and your family during your treatment with GIVLAARI for the acute porphyrias. Details about the program can be found in the Alnylam Assist® Brochure, which introduces the program and how to begin the service. Explanation of Benefits (EOB), which outlines what these EOBs contain and how to understand them and the Alnylam Assist® Caregiver Brochure, which offers support tips and practices, as well as communication with the healthcare team. If you have questions for the Alnylam Team, please call 833-256-2748. See *https://www.alnylamassist.com/*

Panhematin Assistance - Recordati Rare Diseases maintains a support program, which can help caregivers, doctors and medical staff, and others who have questions about PANHEMATIN insurance coverage and related issues as well as financial assistance. Contact the Recordati Rare Diseases Patient Support Program hotline at 866-209-7604. This helpful program provides financial assistance, including assistance for underin-sured or non-insured patients and co-pay insurance to gain access to Panhematin treatment. In addition, their Patient Liaison (PL) program provides one-on-one support for patients and caregivers. See https://www.panhematin.com/personalized-support and fill out the Opt-In form. Helga is their patient liaison, and can answer any questions and provide personalized assistance.

Scenesse Assistance - Clinuvel Pharmaceutical maintains a program to aid in accessing Scenesse for EPP. The Scenesse patient assistance programs (PAPs) can help eligible patients pay for the cost of treatment. These programs can offer discounted or free medicine, as well as copay assistance programs. Patients must have a confirmed diagnosis of EPP. Please see *https://scenesse.com/public/patient-assistance-program/* and contact the APF at 1-866-APF-3635.

ADVOCACY

Presentation In Pakistan

Abdul Waheed Butt, a dedicated APF member and the leader of the Pakistan Porphyria Support Group, recently had the honor of presenting on porphyria at the University of Islamabad. Abdul spoke on each type of porphyria and shared his personal journey with the extremely rare Congenital Erythropoietic Porphyria (CEP). His candid account highlighted the challenges and triumphs he has faced, providing valuable insights to the audience. Congratulations to Abdul for his commendable tireless efforts to raise awareness about porphyria in Pakistan.

Porphyria Pain

ABRAPO - Associação Brasileira de Porfiria, the Brazil Patient organization heacded by Ieda Bussman, has produced an extraordinary video on Porphyria PAIN, https://www.youtube.com/watch?v=oGstgV6G7ZI . Pain is a subject that has great significance for the porphyria patient community. This is why the APF has been intrinsically involved with the major Pain programs to help mitigate the many misconceptions and misinformation about pain. Frequently, we hear from patients that the medical community will not believe the level of pain patients are experiencing. Often the “drug seeker” tag is placed in their medical records. The APF, like ABRAPO, is at the forefront of combating these demeaning circumstances through government programs, publications and relating patient stories at every opportunity to the public, the media and government officials

ANNOUNCEMENT

Porphyria Awareness Week

It is almost time again for PAW again!!! Our annual Porphyria Awareness Week (PAW) will take place from May 12th - 18th culminating in Global Porphyria Day on May 18, 2025. This dedicated week serves as an opportunity for individuals affected by porphyria to engage with their friends, family, and communities to raise porphyria awareness.

At the American Porphyria Foundation (APF), we are committed to enhancing awareness of porphyria throughout the year; however, during PAW, we encourage our members to take an active role in this crucial effort. We invite you to help us spread awareness by sharing information with medical offices, reaching out to your local media to promote your personal journey with porphyria, and educating your friends and family about the disease and the many challenges you face. Together, through our collective efforts during Porphyria Awareness Week, we can make a meaningful impact and foster a greater understanding of porphyria in our communities. In the past, many of our members held fun events: motorcycle races, mud wrestling, nighttime runs, horseback rides, and hikes through the Appalachia. Others placed brochures in doctor’s offices, held cook-offs, etc. Lots of dogs were wearing APF pet bandanas. Having the patient community advance porphyria awareness is the most powerful means to heighten Porphyria as a disease that needs attention. One family has two children with CEP, an extremely rare type of porphyria and they do an annual blood drive every year for PAW. There is a blood shortage in their area, so they are helping others in their community not only by creating awareness about porphyria but also by promoting the importance of blood donation in general for those who are able to do so. The APF will supply materials if you would like to host an event. Lastly, many people contacted their local media, who then featured the porphyria friends on local and na-tional media. We look forward to seeing you on TV and radio, in newspapers and podcasts! The APF will show you how to gain this attention to your disease, so please reach out if you would like assistance. Thank you for your support!

EXCITING NEWS...

After taking a hit from Hurricane Milton, we are thrilled to share that the APF has relocated to a new office in Sarasota, Florida! Our phone numbers are the same, so feel free to reach out. Our new address is **6605 33rd St E Suite C, Sarasota, Florida 34243**. If you are nearby, we would love for you to drop by! It is always a pleasure to meet our amazing members. And if you are looking to get involved, we could use your help in the office – especially with distributing tons of requests for our educational materials. We are so proud to say that despite the challenges posed by the hurricane, we kept our patient services running without a hitch! We seamlessly forwarded our phones and materials to our staff in areas not affected by the storm, ensuring we were there for every caller and fulfilled every request, even during the evacuation. Talk about dedication, right? We could not have done it without our incredible APF team!

FREE DNA ANALYSIS FOR ACUTE PORPHYRIAS REESTABLISHED

After a brief interruption, the Free DNA Analysis program has become available again for acute porphyrias. If you are interested in receiving DNA testing, please contact the APF to receive the form for free DNA test-ing by emailing general@porphyriafoundation.org. The form is included in the comprehensive acute doctor packet, which is widely distributed by the APF. Ordering the test is a simple procedure. The eligibility criteria are on the form. Note that all testing must be ordered by a qualified Healthcare Provider. You can have the test sent to your home or order it to be done in your physician's office. Prevention Genetics advised the APF that the most accurate results come from doing the buccal swab in the doctor's office. If you choose the at-home test kit with your doctor, please be sure to follow the instructions closely. We appreciate Alnylam Pharmaceutical for providing this vital testing project via their Alnylam Act program.

Down Memory Lane

In the early days of the American Porphyria Foundation (APF), founders James Young and Desiree Lyon met with the pioneering support group leaders, Herta and Hermann Woerner. The Woerner's son, Roland, played a crucial role in the initial years by producing the first APF awareness video on porphyria and the foundation.

After graduation, Roland enjoyed a remarkable career as a producer for the "Today Show" and other television news outlets, as well as a successful documentary filmmaker and writer. His ongoing support for the APF has been instrumental in increasing media attention on porphyria, shining a light on this often-overlooked condition and helping to connect affected individuals with vital resources and information. Since that time, the APF has produced many videos and ZOOM presentations which can be found on our You Tube channel. Put porphyria on the medical map! You, too, can help by using your talent to aid the porphyria message. Please contact the APF.

3700 Doctor Packets Sent

Did you know that patients and physicians in 120 countries request porphyria information from the APF? In turn, they receive a very comprehensive doctor packet, which includes instructions for diagnosis, information on specific treatments for each type of porphyria, research articles and notices of research studies. Plus, in the US and Canada, we include forms for free DNA tests for acute porphyrias. Last year, we sent 3700 doctor packets here in the US plus hundreds distributed at medical conventions. Many doctors have commented that they particularly appreciate that the most essential porphyria information is compiled for them in the packet and can be easily accessed and easily added to their patient portals. If you want a doctor's packet sent to you or your physician, please contact the APF at 866-APF-3635 or request a packet at Pax@porphyriafoundation.org or general@porphyriafoundation.org. The packets arrive by email so you can easily forward them to all your physicians and medical teams. You can also order the printed packets for a feephyria on the medical map! You, too, can help by using your talent to aid the porphyria message. Please contact the APF.

APF PODCASTS WORLDWIDE- Among the many Rarely Discussed interviews at the International Porphyria Congress were new SAB board member, Francesca Granata , PhD, who is a molecular biologist and Porphyria expert, known for her Ted Talk titled, "How to step out from the shadows." She shares her experiences as an erythropoietic protoporphyria (EPP) and scientist in Italy. https://www.youtube.com/watch?v=8CnjC56xCkY . Also interviewed was Derry Wilcox, Treasurer for the Global Porphyria Advocacy Coalition (GPAC) and the Canadian Association for Porphyria. He shares how journeling helped with his Variegate Porphyria (VP) diagnosis. https://www.youtube.com/watch?v=y3hNYq6yqac . Another terriffic guest is Nadezda Pejovic, founder of the National Associations of Porphyrias of Serbia, who related how being a pharmacists helped with her AIP. https://www.youtube.com/watch?v=rBhaHnlCsSI

IN REMEMBRANCE

Great Sadness And Sympathy

Recently, the APF lost two ardent supporters, Samuel Silver, MD and Alberto Recordati. PhD.

Dr Samuel Silver was a highly awarded and esteemed porphyria expert at the University of Michigan in Ann Arbor whose clinical practice focused on classic and malignant hematology, with a particular focus on porphyria. Dr Silver served on the APF Scientific Advisory Board and provided his expertise for physicians around the country who needed assistance with their porphyria patients. After 36 years at the University of Michigan Medical School, he retired as Professor of Medicine. We extend our sympathy to his beloved wife, Nancy, and his devoted family and thanks to the gifts in Dr Silver's memory.

Dr. Alberto Recordati was also a great supporter of the APF. When Recordati Pharmaceuticals in Milan, Italy purchased Normosang and Panhematin, Dr. Recordati developed an interest in supporting patient care. Dr. Recordati joined the Recordati company after he graduated from King's College of London University, where he earned a degree in bio-chemistry. After an award-winning career in numerous roles at the company, he was appointed Chairman of the Board of Directors until he retired. His interest in the porphyrias and the APF continued until his passing. The APF extends our deepest sympathy to his family and thanks everyone who made gifts in his memory.

APF friends often give donations in memory or honor of their dear loved ones. We are grateful for each of them.

IN MEMORY OF

In Memory Of Donna Pagano, Kathleen Toelkes
In Memory Of Clinton Lucas,Paul & Barbara Mellon
In Memory Of Jim Lucero, Beverly Roberts
In Memory Of Rev. Darlene Bishop, The Montgomery School & Linda Jones
In Memory Of Mila Castellano, Eunice Richmond
In Memory Of Jon Klopfenstein, Susan Wetzel
In Loving Memory Of Dr. Samuel Silver, Desiree Lyon and Nicole Castellano
In Memory Of Carol Rusnak, George Rusnak
In Memory Of Ed Hailey, Davis Nolan
In Memory Of Camden Meredith Nuckols, Susan Nuckols
In Memory Of Kelli Quenzer, Gary & Nicole Quenzer
In Memory Of Alann Green, Alicea Family, Desiree Lyon and Nicole Castellano
In Memory Of Paolo and Bruno Castellano, Nicole Castellano

IN HONOR OF

Rodney & Cynthia McCabe In Honor Of **Nicholas Guanciale**
Michael Nichols In Honor Of **Katayuki**
George Rusnak In Honor Of **Diana Sabella**
Rose Marie Gasper In Honor Of **Amy Burke**
Rosemary Houlihan In Honor Of **Leo Wagner**
Ben Langdon In Honor Of **Luke Langdon**
Marcia Alicea In Honor Of **Tasha & Kalel Alicea**
Connie Helleson In Honor Of **Jennifer Streeter**
Nicole Castellano In Honor Of **Felicia Bennett and Family**
Anne & Walter Tucker In Honor Of **Kevin Tucker**
Charles Davis In Honor Of **Ginger Davis**
Donna McGlaughlin In Honor Of **Kristen Steinhilber**
Lori Hanson In Honor Of **Ralph Gray**
Desiree Lyon & Nicole Castellano In Honor Of the **APF Member Advisory Board - Andrew McManamon, Terri Witter, George Hodder, Steve Ferry, Debra Knapp, Claire Richmond, Gudrun Debes, Tasha Alicea and Justin & Holly Hamilton**
Nicole Castellano and Desiree Lyon In Honor Of **Dr. Roy E. Smith**

DONATIONS WELCOME

YOUR HELP IS NEEDED
after Hurricane Milton

Please consider the APF in your giving. Our Bradenton, Florida office was impacted by the devastating Milton hurricane, which necessitated our relocation to a new office nearby in Sarasota. Despite the challenges this situation has presented, the APF has remained committed to assisting patients every day without any disruption in our services. However, we urgently need your help to replace many of our brochures and publications. Additionally, we are seeking donations to strengthen our comprehensive physician education program. As our patient population continues to grow, so does the need for updated materials to provide specific guidance for doctors on how to accurately diagnose and treat all types of porphyria. By supporting us, you are not just donating; you are joining our fight for understanding and better diagnosis and treatment for porphyria patients. To contribute, please visit our donation page at https://porphyriafoundation.org/get-involved/donate. Together, we can make a meaningful impact and bring hope to those living with porphyria!

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 that consult with personal physician or local treatment center before pursuing any course of treatment.

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Donate to the APF

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

THANK YOU!

The APF does not receive government funding. Your contributions help educate physicians and patients with life-saving information about the porphyrias. Donations are tax deductible. Become an APF member today!

UPDATED CONTACT INFORMATION?

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

Address Service Requested

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