AMERICAN PORPHYRIA FOUNDATION

AUTUMN 2025 **NEWSLETTER**

IN THIS ISSUE

GRATITUDE, RECOVERY, AND A PROMISE TO KEEP GOING, APF EXECUTIVE DIRECTOR NICOLE CASTELLANO

Dear APF Community, Over the past few months, you may have noticed that I haven't been as visible or present as usual and an absence from our podcast. I want to take a moment to share why that is and to thank you for your continued support, patience, and trust during this time. Earlier this year, I had to have two serious cardiac surgeries — including open-heart surgery — followed by additional interventions to address complications during recovery. It has been a physically and emotionally demanding experience, made even more complex by my having porphyria — something many of you can relate to when facing other major health challenges. The road to healing has been longer than expected, and I'm still on that journey.

To ensure a full recovery, I've had to take a step back to focus on healing. But I want to assure you that I'm still here and still deeply committed to the mission of the American Porphyria Foundation. Thankfully, our co-founder, former Executive Director, and my dear friend Desiree Lyon — who also serves on the Board of Trustees — has graciously stepped in during this time. Her wisdom, experience, and deep love for this community, along with the support of our staff and the rest of our Board of Trustees — Paul Stickler, Warren Hudson, James Young, Diana Ijames, and Ron Polly — have helped keep everything moving forward so that no part of our mission has been left behind. I could not be more grateful for their support — and for yours. When I return, I look forward to sharing more of this journey — including how porphyria impacted my recovery. So many in our community face complex medical issues beyond porphyria itself, and I hope that sharing my experience can support others who are navigating that intersection. To our patients, families, physicians, researchers, advisory board members, and industry partners — please know that I remain dedicated to each of you and look forward to continuing our mission to improve the lives of all those impacted by porphyria. Until then, the fierce resilience of our Porphyria family reminds me every day why this work matters and how honored I am to be a part of it. I can't wait to come back stronger than ever! 💜💪 Nicole Castellano

THE APF IS MAKING A DIAGNOSTIC IMPACT

Recently, a young man sent us an important message. The APF had helped him and his family secure a diagnosis of AIP a number of years ago. When he visited the NAVY recruitment office. to his surprise, the recruiter asked one of the standard questions, " DO YOU HAVE PORPHYRIA ?" It appears that porphyria is on the list of potential disqualifiers due to the potential impact of the condition on military service and its demanding nature. When discussing this news, another AIP person told us that she was disqualified from joining the Marines due to her AIP diagnosis. Although this is not good news for the people who want to join the services, it is good to know that the APF has made such diagnostic inroads that the military services are aware of the porphyrias.

NEW PATIENT AND PHYSICIAN EDUCATIONAL PROGRAMS

Disc Medicine is proud to announce their new campaign to raise awareness for Erythropoietic Protoporphyria (EPP), including X-Linked Protoporphyria (XLP). The campaign was built specifically for people living with EPP and XLP and their caregivers and is intended for US residents to provide: Explanations for Understanding EPP, Tips for managing symptoms, Resources to help build your care plan, Links to support networks and resources.

FOR HEALTHCARE PROFESSIONALS:

Disc has launched a Healthcare Professional (HCP) focused site offering dedicated resources to support clinical practice, including: Disease education on EPP, Diagnosis and testing guidance, Information on long-term management. HCPs please visit: *PPIXiswhyhcp.com* for more information. Disc also has created a video series for EPP management presented by porphyria experts, Bruce Wang, MD Hepatology, UCSF Porphyria Center San Francisco, CA and Gayle Ross, MBBS (Hons), FACD Dermatology, The Royal Melbourne Hospital ,Melbourne, Australia. See the video series here: *PPIX ON Medlive with Dr. Wang and Dr. Ross*

FOR PATIENTS:

Disc Medicine also is committed to deepening the understanding of EPP and XLP in the patient community. Patients, their families and friends will appreciate the exciting new educational program and community of other EPP and XLP patients. Please visit the new website for patients: *www.PPIXisWhy.com* Also see *PPIX IS WHY on Facebook* and *PPIX IS WHY on IG /*

DISC BITOPERTIN TRIALS:

The APF is assisting with recruitment for a Disc Medicine research trial using Bitopertin to treat EPP and XLP. If you are interested in learning more or would like to participate as a research patient for the trial, please contact the APF by email at general@porphyriafoundation.org or call 866-APF-3635. We thank the many patients who have become research volunteers. You are our MEDICAL HEROS !!!

PATIENT EDUCATIONAL AND SUPPORT MEETINGS -a favorite event

WOULD YOU LIKE TO HAVE A MEETING IN YOUR AREA? Our first meeting that has been scheduled will be held at the Hilton Hotel in Venice, Florida on October 26 at 5 PM est. Friends with Porphyria have always enjoyed in person gatherings. Thus, the APF has re-instituted our PATIENT EDUCATIONAL AND SUPPORT MEETINGS throughout the country to address the overwhelming requests for these one-on-one meetings with our porphyria community. Prior to the Covid pandemic, the APF hosted numerous Patient Meetings each year. These gatherings provided a rare and valuable opportunity for patients and their families to meet others affected by porphyria-often for the first time-while receiving medical and emotional guidance in an educational setting. When a meeting is scheduled, the APF will place a notice on our many platforms, including the website, Enews, FACEBOOK, and our Podcast, Rarely Discussed. Invitations will also be mailed to members who live near the meeting city. We look forward to seeing you !!!

To Bring these meeting to life, HOSTS ARE NEEDED Please Be a Host Leader in your area. We Need you to help make them happen! It is easy to be a Host Leader. You help us Identify an accessible location (a home, library, church, hospital, or community room), Be present at the meeting to greet and connect with attendees, Support a warm and inclusive environment for patients and families. Whether two people come or a hundred, the experience of connecting in person is always meaningful. If you would like to become a Host Leader or learn more, please contact the APF Together, we can create a stronger, more connected porphyria community—one city at a time. To become a Host Leader or learn more, please contact the APF. 866-APF 3635 or *general@porphyriafoundation.org*.

NAPOS ACUTE PORPHYRIA DRUG DATABASE

The Acute Porphyria Drug Database is a trusted online resource that helps patients and healthcare providers understand which medicines are safe to use if you have an acute porphyria. It helps guide treatment choices to avoid triggering porphyria attacks.

The present database being used by the APF was developed by the Norwegian Porphyria Centre (NAPOS) at Haukeland University Hospital in Norway and is being used throughout the world. It was started in 2002 by Dr. Atle Brun, who worked passionately for many years to make medicine safer for people with porphyria. In 2005, the database grew from a Nordic (Scandinavian) resource to an international one, available online for anyone to use. Many experts helped build and improve this database. Professor Stig Thunell from Sweden played a big role in creating the system used to evaluate how safe different drugs are for porphyria patients. 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) contribute to the NAPOS database.

Between 2007 and 2010, the database was expanded further as part of a European project. During this time, patients and doctors from across Europe shared real-life experiences with different drugs, which helped confirm the safety ratings of many medicines. The database is kept up to date by NAPOS in collaboration with porphyria experts and pharmacists from the UK and other international teams. These professionals carefully review new medicines and updates in drug safety. Each medicine in the database is evaluated based on a scientific method published by researchers in 2007. This method helps determine if a drug could trigger a porphyria attack or if it's likely to be safe. We are most grateful to the Norway Porphyria Center and the experts worldwide who assist in this valuable service to patient and their physicians.

NEWS FLASH!

ALL PATIENT STORIES are on the APF WEBSITE: *https://porphyriafoundation.org/for-patients/member-stories/* and ALL APF PODCAST STORIES NOW STREAMING The APF Podcast, Rarely Discussed is now just one click away on our website! Dive into amazing patient stories, exclusive interviews with top doctors, and so much more—all in one place. Listen or Watch at :

https://porphyriafoundation.org/podcast/

ACUTE ATTACK ON MOUNT EVEREST

Nancy Pometta first experienced the devastating effects of Acute Intermittent Porphyria (AIP) while hiking the legendary Mount Everest—a moment that would change her life forever. A Seattle, Washington resident, Nancy had spent the past ten years struggling with unexplained abdominal pain and bouts of vomiting. Despite numerous referrals to gastroenterologists, the consensus remained the same: it must be dietary. But the real cause was far more serious—and it was about to reveal itself. In September 2023, Nancy embarked on the adventure of a lifetime, traveling to Nepal to trek Mount Everest. Near the end of her journey, she was hit with severe leg pain and a debilitating weakness that left her desperate to return home. Back in Kathmandu, her condition worsened. Battling unbearable pain and vomiting, she prepared for the harrowing flight back to the United States.

Once home, things took a terrifying turn. After waking from a nap, Nancy found she couldn't stand—her legs had collapsed beneath her. Rushed to the hospital, she rapidly deteriorated. Paralysis set in. Her sodium levels dropped dangerously low, while her blood pressure soared. She was moved to the ICU, then transferred to another hospital, where she remained for two months. Her arms and legs remained immobile for four more months. Doctors initially suspected Guillain-Barré Syndrome, but when her condition worsened instead of improving, that diagnosis was discarded. Nancy, now completely bedridden, cried herself to sleep at night, convinced she was dying. She had taken a month off work, expecting to return shortly—but instead, her life was consumed by hospitalization and intense therapy.

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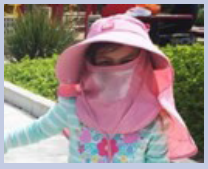
Then, on October 23 at 10 PM—just two hours before her 30th birthday—doctors entered her hospital room with long-awaited news: "We have a diagnosis—AIP." That night, she received her first Panhematin infusion. As her back and abdominal pain began to ease almost immediately, she called it the best birthday present she had ever received. The breakthrough came when doctors noticed her urine appeared reddish-brown—initially suspecting blood. But tests confirmed it wasn't blood. An internist remarked, "I saw this color in medical school." She ordered a urine PBG test, which revealed highly elevated levels—confirming their diagnosis. With the correct treatment underway, Nancy's healing finally began.

Although her muscles had atrophied, requiring months of physical therapy, the Panhematin infusions prevented further attacks and helped keep the excruciating pain at bay. Slowly but surely, she regained strength and began the long journey back to normal life. In 2024, Nancy returned to work. But reintegrating was not without its own set of challenges. Though she appeared well on the outside, some coworkers questioned the severity of her illness, making dismissive comments that stung deeply. Still, Nancy pressed on. The experience only strengthened her resolve to support others with porphyria. Today, she's committed to raising awareness and helping others navigate this rare disease. You can hear Nancy share her powerful journey in her own words on the American Porphyria Foundation (APF) Podcast, Rarely Discussed. Tune in to watch Nancy's story, porphyria friends, doctors and caretakers and others. *https://porphyriafoundation.org/podcast/*

HOPE FOR EPP KIDS



We have announced that a nine-year-old child was successfully treated with SCENESSE in Switzerland by the famous and beloved expert, Dr. Anna Minder. The child was suffering from very severe phototoxicity and was living quite an ordeal as she couldn't participate in daily activities. She basically was living inside the home and sadly could not tolerate any form of light. With SCENESSE she is now living a normal life at home and school. It is the hope of the APF that regulatory agencies will take note of this wonderful event and agree to expand their approval of the SCENESSE label to young patients. Sine Scenesse has been monitored for decades with an amazing safety record consistent with benefit-risk, we hope approval will reach EPP kids.

ANDREW ISRAELSEN Journey to the Sun

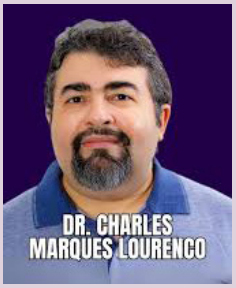
Andrew Israelsen would turn 18 in August, which should have been a moment of celebration. But instead. He and his family received disappointing news: Andrew's insurance provider would not approve Scenesse, the only treatment for his EPP, because he was still underage and only three months from his 18th birthday. For Andrew, who had long dreamed of playing baseball with his school team and joining his family on a Caribbean cruise, the diagnosis of EPP made those hopes feel impossibly out of reach.

That changed when Andrew's father, Rich, reached out to the American Porphyria Foundation (APF). We immediately contacted Dr. Linda Teng at Clinuvel, the manufacturer of Scenesse to explore any possible pathways to help Andrew receive Scenesse early. Unfortunately, the insurer in the U.S. held firm—no access until age 18, just a few months away. But the APF had seen success before. Other members had traveled to Switzerland to receive Scenesse from Dr. Anna Minder, even before the treatment was approved in the U.S. We reached out to her on Andrew's behalf, and she warmly agreed to help. Before departing, Andrew met with Sancy Leachman, MD, PhD, who would be his physician to administer Scenesse in the U.S. once eligible. Dr Leachman helped prepare the necessary paperwork for the Swiss clinic. Antonella Colucci with Clinivel in Europe helped facilitate the clinic visit and with everything in place, Andrew and his mother, Geni, boarded a plane to Switzerland the next day. There, he received his first Scenesse implant from Dr. Minder—who, like always, impressed the family with her brilliance, warmth, and compassion.

Shortly after returning home, the family set off on their long-awaited cruise. Uncertain whether the Scenesse would take effect in time, they held their breath. But just days later, the APF phone rang—it was the Israelsens, calling joyfully from the ship. Andrew had been swimming, enjoying watersports, and basking in the sun with his family—without pain. Their relief and happiness were overwhelming. None of it would have been possible without the dedicated efforts of so many. The Israelsens expressed their heartfelt gratitude to Nicole and Desiree at the APF, Dr. Linda Teng and Antonella Colucci at Clinuvel, Dr. Anna Minder, and Dr. Jasmin Barmen at the Zurich clinic. Together, they helped make Andrew's dream a reality—and gave him a new life under the sun.

DR CHARLES LOURENÇO MD, PhD ON APF PODCAST

If you have not viewed Dr. Lourenco on the APF Podcast, it is a must see!!!!!



Dr. Lourenço is a renowned clinical biochemical geneticist from the University of São Paulo, Brazil and Professor at Centro Universitário Estácio de Ribeirão Preto specializing in genetic neurogenerative disorders. , Dr. Lourenço also is an esteemed member of the APF Scientific Advisory Board. He joins Andrew McManamon on the APF Podcast. Affectionately known as "Dr. Charles" in Brazil, he is recognized as one of the world's leading experts and researchers in porphyria. Following advanced training with experts, Dr. Lourenço began participating in International Porphyria Congresses and collaborating with experts worldwide. Today, he stands as a respected authority in the field. As a clinical biochemical geneticist, his work has significantly advanced the understanding, diagnosis, and treatment of both hepatic and cutaneous porphyrias.

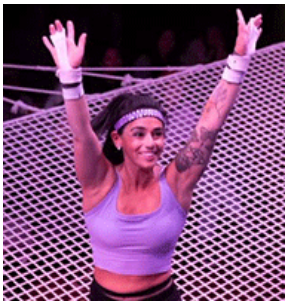
Dr. Lourenço's research has addressed complex issues such as porphyria-induced paralysis and rare dual diagnoses. His commitment to improving diagnostic testing and patient care has had a global impact. Whether speaking at international conferences or guiding clinicians through challenging cases, he brings clarity, compassion, and expertise to a condition that is often misunderstood. In this episode, Dr. Lourenço discusses critical topics for patients and caregivers alike—including the widespread misconceptions about carbohydrates in acute porphyrias, who is most at risk for attacks, the importance of accurate diagnosis, the role of DNA testing and answers to many of the questions patients ask every day. We are honored to welcome Dr. Lourenço to the APF Podcast as he helps illuminate the path forward for those living with porphyria. https://www.youtube.com/watch?v=MVPa7d_qKOM

JASMIN BARMAN-AKSOZEN, PhD

A leading voice in porphyria research, working at the Swiss Reference Center for Porphyrias at the Municipal Hospital in Zurich. She is also a Principal Investigator and Lecturer at the University of Zurich within the Research Priority Programe Innovative Therapies in Rare Diseases (ITINERARE) and a member of the APF Scientific Advisory Board. Her work spans the scientific, ethical, legal, social, and health-economic dimensions of treatments for rare diseases—especially porphyrias. One of Dr. Barman-Aksözen's current projects examines the design of clinical trials for emerging pharmacological treatments for erythropoietic protoporphyria (EPP). Conducted in collaboration with the International Porphyria Patient Network (IPPN), researchers at the University of Zurich, and other rare disease organizations, the study reveals that most EPP trial protocols are difficult to compare directly. For instance, while the afamelanotide trials measured minutes spent in sunlight without pain, other studies measure time spent outdoors—a fundamentally different metric. Even more concerning, some protocols require patients to expose themselves to sunlight until symptoms occur, raising serious ethical concerns. As EPP pain is both untreatable and often severe, these trial requirements are ethically questionable.

A second area of focus in Dr. Barman-Aksözen's research is the genetic investigation of complex acute hepatic porphyria cases. In collaboration with her former student, Adrian Belosevic, they recently uncovered a striking case of mosaicism in a patient with Acute Intermittent Porphyria (AIP). While the patient's biochemical profile confirmed AIP, no genetic mutation could initially be detected using standard blood tests. With advanced Nanopore sequencing and the support of specialized labs, they discovered that the mutation arose early in embryonic development and was present only in certain tissues—particularly the liver. This meant that blood-based DNA or enzyme testing yielded normal results, highlighting the importance of biochemical diagnosis when molecular results are inconclusive. Their findings mark the first documented case of mosaicism in porphyria and underscores the complexities of genetic testing in rare diseases. Note: Mosaicism is a genetic condition where an individual has two or more cell lines with different genetic or chromosomal compositions within their body. This occurs when a mutation arises during early development, leading to some cells carrying the mutation and others not. Mosaicism can be found in various tissues.

MELISSA NAGIN



Melissa "*Missy*" Nagin was a healthy young woman before college. However, during her college years, she began drinking alcohol and using birth control, which coincided with the onset of strange and distressing symptoms. Despite seeking medical help, no one could pinpoint the cause of her pain, skin issues, and overall discomfort. This continued for quite some time until she met dermatologist Dr. Lydia Evans, whose background in hematology gave her a broader perspective. Dr. Evans suspected porphyria and ordered the appropriate tests to confirm the diagnosis. Experts confirmed VP.

After nursing school graduation, Missy moved to St. Louis to begin her career as a bone marrow transplant nurse. It was there that she experienced her first acute porphyria attack. Despite having a confirmed diagnosis and carrying emergency room guidelines from the American Porphyria Foundation, her condition was mismanaged. Treatment was delayed for nearly 10 days, and her symptoms worsened significantly. It wasn't until Panhematin was finally administered that her condition began to improve. The diagnosis, however, did not put an end to the attacks. Seeking better medical support, Missy made a life-changing decision to relocate to Seattle, Washington, where the Fred Hutchinson Cancer Research Center housed a porphyria expert. After the move, a nursing school friend invited her to SANCA—the School of Acrobatics and New Circus Arts. Although she had never been to a circus school before, Missy fell in love and began training in flying trapeze and later expanded to other circus disciplines. Movement and strength-building became both therapeutic and empowering. When she was healthy, she trained and performed; when she was ill, her motivation to get back on the trapeze helped her through recovery.

Today, Missy teaches and performs at SANCA and Emerald City Trapeze Arts. Her porphyria specialist tailors her treatment plan to support her active lifestyle and professional commitments. She embraces life with joy and energy, including a deep passion for world travel, recently spending two weeks in India and previously summiting Mount Kilimanjaro and volunteering in Cambodia—all while carefully following porphyria safety guidelines regarding rest, diet, alcohol, and medication.

A porphyria expert added Givlaari treatment to reduce the number of attacks, which is working well. When Melissa has breakthrough attacks, Panhematin is quickly ordered and infused. Notably, she has a unique prodrome: a haze in her left eye that often leads to complete blackout, signaling the onset of an attack. When this occurs, she heads straight to the ER for treatment. Her doctor has established an ER treatment protocol that includes recognition of her prodrome symptoms. However, Missy or a friend often still need to advocate for proper and timely care. Rapid treatment with Panhematin is crucial to halt the attack early and prevent nerve damage. Her decision to live near a porphyria center was a wise and life-changing one. Missy's inspiring story and resilient spirit will be featured in an upcoming episode of the APF podcast on the APF website Podcast Section: *https://porphyriafoundation.org/podcast/*

CIRCLE BACK TO THE STYX BAND

In her youth, Debra Knapp headed the official STYX band chat room. As such, she became friends with the band members, the staff and was so tied to the band that she learned personal details—like the fact that guitarist James "JY" Young's wife was battling a rare illness. Debra's connection to the band ran deep. She even met her future husband at a STYX concert. After college and law school, Debra pursued a demanding career as a lawyer and left most of her STYX-related life behind—though she remained a devoted fan. While building her legal career, Debra began experiencing unexplained, intermittent health issues. Over time, the episodes became more severe: abdominal pain, a rapid heart rate, overwhelming weakness, and other alarming symptoms made it increasingly difficult to work. Yet despite countless appointments, she still had no clear diagnosis.

Eventually, Debra discovered the American Porphyria Foundation (APF), which helped her finally get diagnosed with HCP, an acute porphyria. With the treatment, Givlaari, and Panhematin to treat breakthrough attacks, Debra is finally on the road to better health. Grateful for the support she received from the APF, she chose to give back by becoming a Facebook administrator, Porphyria Partner providing peer support, and a member of the APF's Member Advisory Board. What Debra didn't expect was to find an unexpected link between her past and present. While reading the APF newsletter, she was stunned to discover that JY, her old friend from STYX, was one of the co-founders of the APF with Desiree Lyon. In her STYX days, she had no idea that the rare illness affecting his wife was acute porphyria was the same condition she would have as a diagnosis. The realization was surreal. In her youth, STYX had been a powerful emotional lifeline. Years later, she found that the bandmember, JY, had helped save her physical life. Her journey had truly come full circle. She was rewarded with tickets to the recent Concert.

CHEERS AND TEARS

Happy One Year Birthday to Georgia Cummings, the daughter of Pax, our Patient Care Coordinator, and his wife, Holland. Georgia was a long prayed for miracle.

Happy Birthday to Dr. Judith Hudson, APF board member and wife of Board of Trustee member, Warren Hudson.

Congratulations to Branden Hamilton for his 12th birthday.

Congratulations to all the many graduates and to all the kids starting back to school.

Cheers to Hannah Leigh Swain for inventing a new, funny but serious way to cover her hands while driving ..a thick pot holder. Although unique, the thick mitt illustrates the fierceness of light on the skin of an EPP sufferer.

Do you have any unique protective measures you use to protect yourself from the light?

ANDREW & LAUREN SMITH Share From Australia

Andrew and Lauren were living full, busy lives in Melbourne, Australia, raising their two young daughters. Life was good—except for one persistent shadow. Since her teenage years, Lauren had suffered from recurring bouts of abdominal pain and a range of unexplained symptoms. Despite seeing countless doctors, she received no clear diagnosis. Most dismissed her condition as psychological, telling her it was "all in her head." Everything changed when Lauren underwent gallbladder surgery at the age of 39. The procedure triggered a catastrophic health crisis. It was during the height of the COVID-19 pandemic, and Melbourne—under one of the strictest lockdowns in the world—had rigid hospital visitation rules. Even Andrew wasn't allowed to be by her side. Lauren's condition rapidly deteriorated. She was transferred to the ICU in critical condition with still no diagnosis. Andrew, a director of an Occupational Therapy clinic, was heartbroken. After a career dedicated to helping others, he found himself powerless to help the person he loved most. Desperate and isolated, he tried everything he could from the outside, but nothing made a difference.

Eventually, Lauren was sent home—still undiagnosed and dangerously ill—simply because the hospital could no longer risk non-COVID patients staying. When Andrew picked her up, she was physically and emotionally shattered. She had lost half her body weight, could barely walk, and was traumatized from weeks of pain, hallucinations, and isolation. Determined not to give up, Andrew dove into researching Lauren's symptoms and came across Acute Intermittent Porphyria. He immediately called Lauren's doctor, who told him that porphyria testing had just been sent off as a last resort. AIP was the diagnosis. Treatment began right away. Lauren started receiving Panhematin infusions, which significantly reduced the frequency and severity of her attacks. Because her episodes were hormone-related, she was also prescribed hormonal therapy to stop her menstrual cycle—a measure that helped for a while but has since become less effective.

Throughout this difficult time, Andrew reached out for support. The British Porphyria Association offered guidance, while the American Porphyria Foundation (APF) became a vital source of information. He also connected with the Australian Porphyria Society and eventually joined its board, channeling his occupational therapy background into advocacy and support for others living with porphyria. That knowledge proved invaluable a year later when Lauren's sister suffered a critical porphyria attack and also ended up in the ICU. This time, they were ready—and able—to help. The experience changed their lives. Andrew and Lauren made conscious decisions to prioritize family and health. Andrew launched his own business to allow more time at home. Despite the trauma and pain of Lauren's illness, the Smiths emerged stronger—closer, more intentional, and deeply committed to helping others in the porphyria community. They continue to share their story in hopes of raising awareness and offering support to those who feel lost and unheard. Their journey will be featured in an upcoming APF podcast, where they'll tell others what they wish someone had told them: that they're not alone, and that answers—and hope—are out there. https://porphyriafoundation.org/podcast/

PHARMA FRIENDS Josh Stern

My name is Josh Stearn, and I serve as the Senior Director of Marketing at Recordati Rare Diseases. Over the past 20+ years in the healthcare industry, I've had the opportunity to work across a variety of therapeutic areas. However, I've found the greatest meaning in focusing on rare and ultra-rare diseases—such as Acute Intermittent Porphyria (AIP)—where the impact on patients and their families is profound. I'm especially passionate about partnering with advocacy groups and organizations to raise awareness and drive education around conditions that are often overlooked, yet deeply affect those living with them and their support networks.

Although I've lived in many parts of the U.S., for the past 22+ years, I've called Northern New Jersey home. I live there with my wife, Lauren, our two daughters, Lainey and Remi, and our mini golden doodle, Oliver. When I am not working, I am attending my kids' sports activities and playing my favorite sport, golf.

Editor's note: *We thank Josh for assisting the many acute patients in need of Panhematin treatment. Whether late at night or very early in the morning, Josh is available to assist the many patients who contact the APF for help. With patience, kindness and compassion, Josh rushes to provide for the every request of the APF in behalf of our members.*

ASH AND LIVER MEETINGS

AASLD The Liver Meeting®

American Association for the Study of Liver Disease or The Liver Meeting is the biggest gathering of the global hepatology community is held November 7-11 in Washington, D.C. With access to the latest breakthroughs in liver disease research, practical tools for patient care, and a powerful network of experts shaping the future of hepatology and liver health.

American Society of Hematology or ASH is the world's largest professional society of hematology clinicians and scientists who are dedicated to conquering blood diseases. The 67th ASH Annual Meeting will be held at the Orange County Convention Center in Orlando, Florida, December 6 - 9, 2025. The APF will maintain an exhibit booth at the ASH and Liver Meeting conventions where we will distribute our educational materials and meet with hematologists, hepatologists nurses, etc from around the world. It is also where we learn about the many doctors who treat porphyria. We will need your help to man the exhibit booth. If you can help, please contact the APF at 866.APF.3635 or general@porphyriafoundation.org

IN MEMORY AND IN HONOR

On behalf of the American Porphyria Foundation, we extend our heartfelt gratitude for your generous donation made In Memory or In Honor of your loved one. Your gift is not only a tribute to someone special, but also a powerful act of compassion that will help improve the lives of all those affected by porphyria. Each contribution in memory or honor of a loved one carries with it a story, a legacy, and a reminder of the bonds we share as a community. Your kindness helps fund vital education, patient support, and research—ensuring that we move closer to a future with better treatments and greater hope. Thank you for allowing us to be part of this meaningful tribute. We are deeply honored by your trust and support.

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

IN MEMORY OF

Gary Horn in Memory of **Sandra Horn**
Alison Posel in Memory of **Michael Eric Linner**
Sean and Cheryl Delaney in Memory of **Josephine N. Dzygala**
Robert & Julie Coiro in Memory of **Josephine N. Dzygala**
William and Ann Marie D'Angelo in Memory of **Josephine N. Dzygala**
Phyllis Greco in Memory of **Josephine Dzygala**
Messuri Kathleen **Josephine Dzygala**
Kristin Boynton in Memory of **Franklin Ross**
Susan Harrison in Memory of **Franklin Ross**
Melissa George in Memory of **Franklin Ross**
Carol Fay in Memory of **Franklin Ross**
Davis Nolan in Memory of **Ed Hailey**
Kathleen Toelkes in Memory of **Donna Pagano**
John and Colleen Pearce in Memory of **Anne Holquist**
Megan Rockey in Memory of **Anne G. Holquist**
Virginia Brown in Memory of **Alana Brown**

IN HONOR OF

Cynthia McCabe in Honor of **Nicholas Guanciale's Birthday**
Michael Dimoff in Honor of **Mike Dimoff**
Diane Rocchio-Cohen in Honor of **Melissa Nagin**
Karen and Eric Ginsburg in Honor of **Melissa Nagin**
Jolie Harmon in Honor of **Melissa Nagin**
Andrea and Richard Kringstein In Honor of **Melissa Nagin**
Lori Monville in Honor of **Meghan Monville**
Michael Nichols in Honor of **Katayuki**
Beverly Roberts in Honor of **Judy Lucero**
George Rusnak in Honor of **Diana Sabella**
Carolyn Cafasso in Honor of **Adam Cafasso**
Hilary Cooperman in Honor of **Nicole Castellano**
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