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## Recordati Helps Ukrainians with Porphyria

The situation in the Ukraine is desperate for acute porphyria patients. Sadly, patients are dying. There is ZERO access to testing in the area affected by the war, and access to human hemin treatment is challenging. Sandrine and the Recordati Rare Disease team have gone far and above what is expected of a Pharmaceutical Company by caring for the Ukrainian refugees and providing Normosang/hematin to treat the Ukrainian refugees free of charge in Poland and other countries. The medical team in Warsaw porphyria reference centers and other

centers in Poland also provided care no charge and were complicit in saving the lives of porphyria patients. Sandrine and the Recordati team also provided Normosang/hematin to the patients trapped in the southeast of Ukraine. Transportation is a challenge because air space is closed. Luckily, a man whose family lives with porphyria is dedicated to helping and is serving as a local coordinator.

We thank Sandrine and the entire Recordati Rare Diseases Teams for their humanitarian efforts. Their compassion is saving the lives of Ukrainians with acute porphyria.

### 2022 PRESIDENTIAL AWARD



Sandrine Girardot, Region Alliance Manager for European Recordati Rare Disease, and her colleagues in Poland and Paris are providing Normosang/hematin treatment to Ukrainian refugees and those who remain in the Ukraine. Recognizing these efforts, the APF bestowed them with the 2022 Presidential Award.

## The APF and the Canadian Association for Porphyria Foundation Collaboration

The APF and our friends at the Canadian Association for Porphyria are working together to help Canadian EPP patients gain access to SCENESSE in Canada. As the APF has many Canadian members who suffer from EPP, we felt it important to help our Canadian friends also have EPP treatment. Canadian Association vice

president, Michelle Capon, is leading the charge from Canada. Michelle works in the field and is familiar with the application for new drugs and navigating the Canadian Healthcare landscape. We look forward to this important collaboration. We have held a ZOOM call with more to come.



Canadian Association for Porphyria Vice President Michelle Capon

## New Board of Trustees Member



Nicole Castellano has AIP and will serve as the first woman member on the board of trustees.

Nicole Castellano brings a special perspective to the Board of Trustees because she lives with AIP and understands the struggles of living with porphyria. Nicole started advocating, volunteering and fundraising for the APF in 2017. She hosts *Let's Talk Porphyria* and heads the Pet Calendar Contest fundraiser. She openly shares her porphyria journey to connect with

other patients and spread awareness of this rare disease. She's shared her story on *Behind the Mystery* on *The Balancing Act* on Lifetime TV, the podcast *Gastro Girl*, and in *Authority Magazine*. Because Nicole speaks Spanish and Italian, she's been able to support porphyria patients in

other countries as well as the United States. She received the APF's 2018 Presidential Award.

Nicole is a World Class Pairs Skating champion with her brother, Paolo. She graduated from Northwestern University in 1995 with a double major in theatre and anthropology. After college, she became a private pilot and enjoyed flying with her dad.

Nicole is an entrepreneur and since 2000 she has started several businesses. Currently, she is working as a mortgage loan originator and writing her first book. Nicole lives in Sarasota, FL with her fiancé Mike Lynch and her vizslas, Mila and Laszlo.

## The APF and Pets

The APF annually conducts activities involving pets because our animals are central in the healing process of any illness. According to the Mayo Clinic, pets have the power to help heal patients experiencing emotional or physical pain. Pet therapy is now a growing field that uses animals to assist people coping with health problems.

A study in the Netherlands offered these interesting findings, particularly with larger animals, like cows and horses. The human/animal relationship goes well beyond the superficial, the practical, and the useful: Our connection to animals is so intense that it changes our physiology. Spending time with an animal can influence blood pressure, heart rate,

hormones, and how the body releases and uses vital neurotransmitters.

Below are findings from various studies about the emotional and physical effects pets can have on their human friends.:

- **DECREASE STRESS** – A study from the State University of New York noted that people experienced less stress when performing a task in the company of their pet.
- **LOWER BLOOD PRESSURE** – Owning a pet has the potential to lower blood pressure. This finding is associated with the decreased level of stress people experience while being around their pet.
- **EASE PAIN** – According to Mayo Clinic, pets have the power to help heal emotional or physical pain.
- **IMPROVE MOOD** – People who own a pet tend to be happier,

more trusting and less lonely than those who do not. Pet owners are also less likely to visit the doctor for minor issues.

- **SOCIAL MAGNETS** – Pets attract people. If you are not the best at socializing, take your dog to a nearby park and see how others naturally become drawn to your furry friend.
- **PREVENT ALLERGIES AND IMPROVE IMMUNITY** – The germs that pets bring into the house can help boost your immunity, which will help prevent colds and other mild illnesses.
- **IMPROVE FITNESS** – All dogs need regular exercise to be happy and healthy and coincidentally, we humans need exercise too! Dogs can give you that extra motivation to take a walk around your neighborhood.

## Love is in the Air

Wedding Bells ring for four couples in the porphyria community. Congratulations!



Eileen Hudson and Kike Williams recently married in Chile. Eileen has AIP and heads the Chile Porphyria Society.



Claire Richmond and Michael Wagler's wedding is scheduled next year in Iowa. Claire lives with AIP and writes the patient column for PorphyriaNews.com.



Nicole Castellano and Mike Lynch are getting married in Florida. Nicole lives with AIP. She raises porphyria awareness on social media, through Zoom community calls and annual APF fundraisers.



Warren Hudson, the Chairman of the APF Board of Trustees, and Dr. Judith Miller will be married in Wisconsin this fall. Warren's supported the APF for decades, and Dr. Miller serves on the Scientific Advisory Board, specializing in pain psychology.

## New Advisory Board Member

Mayra Martinez is the newest member to serve on the APF Member Advisory Board. This is a group that advises Desiree on patient matters. Mayra's been an active APF member since receiving her diagnosis, contributing videos of her attacks that have helped others feel less alone. Mayra's husband Wilson also gave caretakers an inside view of the important role they provide in supporting their loved one.

Mayra now has the opportunity to expand her expertise and influence as a patient on the Member Advisory Board.



With the help of her husband, Wilson, Mayra Martinez created videos of her attacks to show other patients what her pain and struggle look like. She is now the newest patient of the APF's Member Advisory Board.

## A 40th Birthday Celebration

Attendees of the International Porphyria Congress celebrated the APF's 40th birthday. It was moving to have patients and doctors, who've known the APF for decades, show their respect for the first and largest international patient organization.

Among those celebrating were Dr. Angelica De Lima, our Protect the Future trainee from Brazil, and Ieda and Bene Bussman, leaders of the ABRAPO Brazilian Porphyria Association. APF membership is

16,400 strong, and we're admired as an organization throughout the world.



Desiree poses with a birthday cake at last month's International Porphyria Congress.

## An Author with EPP Supported the APF

Robert Waller, author of the *Bridges of Madison County*, was a long time supporter of the APF. Robert had EPP and helped the porphyria community by writing a poignant letter to the FDA and other government entities to help them understand the grave need for an EPP treatment.

In the early 90s, Robert called the APF and spoke to Desiree. "He told me his upcoming novel was sure to be a phenomenal success with huge financial rewards." She was surprised of his confidence, but he intended to donate proceeds of his book and wanted to know more about the APF.

She told him the motto was "Patients First" and explained about the educational, awareness, and research programs that support porphyria. "He must have liked the answers because he told me we would be receiving a donation and that I would hear from him again." His book was so popular it gave way to a movie, starring Clint Eastwood and Meryl Streep.

Robert grew up on an Iowa farm and received whippings for avoiding outdoor chores. His family misinterpreted his EPP pain as laziness. "He told me few people believed his burning pain," Desiree said. "But Robert wanted to help



*Bridges of Madison County* bestselling author Robert Waller lived with EPP and supported the porphyria community throughout his lifetime.

others by supporting the APF throughout life, and even in his passing."

## Letter to Netflix about *Midnight Mass*

*Midnight Mass* is a Netflix series that many with EPP found disturbing. On behalf of members, the APF sent a letter to Reed Hastings, CEO of Netflix.

Dear Mr. Hastings,

The American Porphyria Foundation (APF) represents 16,400 people whose lives are affected by porphyria, a group of rare metabolic diseases that cause debilitating pain and extreme light sensitivity. The APF is disturbed by the portrayal of Erythropoietic Protoporphyrin (EPP) in the recent Netflix program, *Midnight Mass*. In Episode 6 of the program, a virus that causes people to become blood thirsty killers is linked to people suffering from EPP. It reinforces harmful myths that negatively impact people living with this terrible disease. To illustrate the plight of EPP people, one person

declared, "Choosing to go out in the sun is like choosing to set myself on fire." Another patient shared that asking him to step into the sunlight is like asking him to put his hand in boiling water.

Children and adults with EPP must avoid sunlight and other visible light sources. Thus, EPP children are automatically isolated from their peers, as well as bullied and taunted as "vampires." In turn, adults, too, suffer an ongoing, life-altering light avoidance battle to prevent swelling and searing pain.

Misleading depictions in popular media are often the only means of awareness of rare diseases, like porphyria, among doctors and the public. Thus, it is the responsibility of media to portray EPP and other rare diseases appropriately. Without

responsible programming, patients are plagued with negative depictions like vampires. Since EPP children are taunted by such portrayals, it is especially important to have a script that is positive and factual.

Please present an apology to the Global EPP community and correct information about EPP in a visible location on your Netflix and *Midnight Mass* websites, and social media outlets, as well as the on the episode 6 credits. People with EPP suffer greatly. Therefore, your actions to remedy the further suffering will be greatly appreciated.

We encourage you to write a letter and send to the following address:

Mr. Reed Hastings  
100 Winchester Circle  
Los Gatos, CA, 95032

# Tasha is Building Community

In 2020, Tasha was diagnosed with hereditary coproporphyrin (HCP). She and her husband live in Arizona with two kids, who also have the CPOX gene. Her son has active disease. When feeling well, she enjoys tubing or kayaking, and is passionate about DIY projects.

At 29, Tasha's symptoms began and she had attacks requiring hospital visits. Despite seeing a host of specialists, no one could discover the cause of her illness. Tasha had major pain and could hardly walk. She went to a new doctor in 2019, who was determined to find a diagnosis. After tests for lupus, multiple sclerosis, and arthritis, she finally tested positive for acute porphyria.

We have had to make some big life adjustments and are learning to navigate this new lifestyle. We have a lot of hard days, but we do have good ones and we hold on to those good days to help get us through. We have so much support with friends that live by us and my husband and daughter are amazing caregivers. I'm so grateful for APF and the Facebook support groups where I can learn and connect with other porphyria patients. It's been a real lifeline.

## PATIENT SUPPORT AND EDUCATION MEETINGS

Tasha Alecia hosted the first face to face rather than virtual meeting in Maricopa, Arizona since COVID began. Interestingly, two attendees were Tiffany and her husband, Kameron Scofield, who lived a mile away from each other in the same small town. They had no idea of another person with porphyria nearby. Plus, both had sons the same age and wanted a porphyria friend who understood their plight. When people with porphyria connect through patient meetings, the outcomes are wonderful.



TASHA ALICEA,  
lives with HCP

Watch the APF website, ENEWS and Facebook groups for details of upcoming meetings. **Want to host a patient meeting in your area? Contact Amy Chapman at [amy@porphyriafoundation.org](mailto:amy@porphyriafoundation.org) or call the APF 866-APF-3635.**

### WARNING!

## COVID ANTIVIRAL DRUG PAXLOVID IS UNSAFE FOR ACUTE PORPHYRIAS

Paxlovid is an oral antiviral drug commonly prescribed after the diagnosis of COVID-19. Made up of nirmatrelvir and ritonavir, which is not safe for acute porphyria, Paxlovid should be avoided for anyone living with AIP, VP or HCP.

# Treatment Guidelines to Come

Givlaari is a treatment for acute porphyria (AIP, VP, HCP) that can reduce attacks. Due to the number of questions we receive about the treatment, here's the latest from physicians and patients.

A recent physician discussion centered around the need for Givlaari guidelines for primary care doctors. Presentations on Givlaari featured patients with positive experiences, but also patients with major side effects. It was wonderful to hear about people whose lives were changed on Givlaari.

However, patients can also suffer serious side effects on Givlaari. The doctors' accounts of side effects were the same as those the APF hears from patients, like elevated liver enzymes and homocysteine levels, significant hair loss, wounds at the injection site and other major difficulties. Panhematin, which has been a treatment for 30 years, and Givlaari can both be effective. Therefore, it is important to discuss with your doctor the treatment best for you.

The APF is advocating for treatment guidelines. Contact us to learn more.

## Fight the Stigma

The following article is a reprint from five years ago. As Director of the APF, I am distressed to say that the article holds true today. As porphyria patients, we continue to be called whiners, hypochondriacs, drug seekers, and a host of demeaning, demoralizing tags that are given to porphyria sufferers by certain members of the medical community, family and others who do not understand this group of diseases. Note in the ensuing article that things have not changed.

Have you ever been called a drug-seeker? A vampire? Has anyone told you that you are just crazy or that this disease is all in your head? We have heard countless times over many years that the stigma associated with those living with porphyria is concerning and demeaning. We have even heard that our members avoid treatment from health care

professionals and that they don't seek much needed support from friends and family because of the negative remarks. The perception of patients living with porphyria won't change unless we help to make the change in the mindset of our communities. As a step, let's focus on physician education. We need to provide a better understanding of the Porphyrias to our physicians to identify and manage it appropriately. Be honest with your physician about the stigma you face and ask your doctor to spread the word about Porphyria in their professional communities. In fighting this reduction in negative experiences for our patient community, it is our hope that demeaning and unproductive behavior will end. That's where YOU come in. Join the fight. Educate. You have a voice. Let it be heard. We are Porphyria Strong. Contact the APF to learn more today.

## A New Global Liason

Kika Shabot, who is the Director of the Mexican Porphyria Society, has become the APF Global Liason. Having begun her tenure with the APF as the hand of friendship and help between the APF and Spanish Speaking patients, Kika's role has now has expanded to Europe and hopefully beyond. As often happens in life, there is a natural progression of activities. People began to see on our social media groups that Kika

was helping us in Latin American, so patients saw her name and began reaching out from other places. Most recently Kika helped patients in Cuba and Turkey. The main role of the APF is to assist US patients, so when people worldwide with porphyria reach out to us, Kika now provides help for them. If you would like to be a part of this effort, please contact the APF and tell them you are open to befriend patients around the world.

## Reunited with a Provider from Brazil

One of the other delights of the Congress was seeing Dr. Angelica DeLima again after many years. Dr De Lima was one of the three global trainees from Brazil, including Dr Charles Lourenco and Dr. Guirme Perini.

Dr. DeLima informed us that although her hospital system would not allow treatment of rare diseases, she was able to treat porphyria because she is a geneticist. We appreciate her and the entire team in Brazil, including the leader of the Brazil Porphyria Society Ieda Bussman and her daughter Bene and son, Janary, all of whom have brought Porphyria Awareness and treatment to Brazil. We congratulate them for their success.



From left: Bene Bussman, Ieda Bussman, Dr. Angelica DeLima, Desiree Lyon

# The Good Days Between the Hard Ones

By Claire Richmond for [PorphyriaNews.com](https://porphyria.com)



Claire Richmond is a patient columnist for [PorphyriaNews.com](https://porphyria.com). She writes about day-to-day challenges with acute porphyria.

I've heard people describe living with a chronic illness like acute hepatic porphyria (AHP) as a full-time job. But it requires much more than 40 hours a week, Monday through Friday. Between medication schedules, doctor appointments, insurance issues, advocacy work, and the healthy behaviors to prevent flare-ups or acute attacks, it can feel all-consuming.

Hitting 5 p.m. on Friday once signified the beginning of the weekend, a time to leave behind the stress of my week. Compartmentalizing a rare disease doesn't work as neatly. There's no taking a break from porphyria.

Sometimes I judge myself for being unproductive and sleeping late. I grow ashamed at the amount of time I spend in bed, the invitations to social events I repeatedly decline, and the time that passes without being what society considers "productive." Everyday tasks take me longer. I can't maintain a routine due to unpredictable symptoms and sporadic medical appointments.

A life with chronic illness is full

of interruptions and setbacks. I never want to be focused solely on porphyria; it's not my hobby.

On a recent morning, I sat in my sweatpants, sipping coffee and scrolling through social media. I "liked" the posts of my peers, who'd received promotions, traveled abroad, or welcomed children into their families, but I felt envious of their freedom.

Energy and financial constraints didn't affect how they achieved their goals or explored their passions. They didn't have to negotiate with their bodies, insurance companies, or medical providers before making decisions.

I want to learn a skill, see the world, and even just complete the projects I start. But that requires a solid foundation I can hold on to, a reliable schedule on which to build.

## ACTIVITIES OF A GOOD DAY

A couple of Fridays ago, I felt pretty good. I'd ridden my electric bicycle to meet friends for our end-of-the-week coffee, a cherished ritual we started on a curb in the midst of the pandemic. Minutes after parking my bike back home, I was covered in garden dirt and giddy with an unaccustomed level of energy.

I delighted in a garden stroll with my clippers in one hand, a vase of cool water in the other. Soon, a bouquet of fresh flowers adorned my dinner table. Then, I peeled off my gardening gloves and luxuriated in hot water running over the back of my hands,

satisfyingly rinsing soil from under my fingernails and just above my wrists.

On a day when I have excess room for movement and additional endurance, my inefficiencies never cease to amaze me. I don't typically consider things like productivity or picking up an abandoned project. I might ride my bike to get a latte. I might watch a butterfly cling to the cosmos I'd haphazardly planted along the sidewalk. I might dig decades-old landscaping rock out from under layers of composted autumn leaves. I might read in the hammock or take a midday walk with a friend.

On a good day, my to-do list doesn't matter. Productivity isn't important when I enjoy being in my own skin. Anytime I can find ways to safely reconnect without resenting, restricting, or feeling scared is critical for my mental well-being, because I have trust issues with my body.

I typically wear leggings and sweatpants and call it my "spoonie style," but I wasn't feeling that look. Instead, I changed into a colorful skirt and sassy graphic T-shirt that better represented my mood. That day, I wasn't wasting my precious, limited energy on doctor appointments. I wasn't going to feel bad about my circumstances. I was leaving my house and going out into the world, and I wanted everyone to know I felt all right.

Thank you to [PorphyriaNews.com](https://porphyria.com) for allowing the APF to reprint!

## What's New?

Check out [www.PorphyrriaFoundation.org](http://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 that consult with personal physician or local treatment center before pursuing any course of treatment.

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## In Memory



APF friends often give donations in memory or honor of their dear loved ones.

Craig Cloud, in memory of his wife  
Karol Cloud

Rebecca Hillebrand in memory of her  
father Derek A.M. Searcy

In memory of Pearl Schwebel and in  
honor of Melissa Nagin

George Runsack in memory of  
Carol Runsak

Wendy Kowalski in honor of  
Theodore Rowland

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](mailto:general@porphyriafoundation.org).

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