



AMERICAN PORPHYRIA FOUNDATION

SUMMER 2022 **NEWSLETTER**

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BREAKING NEWS

TECO Diagnostics Creates Rapid PBG Test

TECO has created a world changing test for the acute porphyrias with their simple one hour urine porphobilinogen/ PBG screening test. The kit is intended for qualitative and semi-qualitative detection of uPBG.

The most common method for diagnosing acute porphyrias is genetic testing, which is costly and not readily available to most patients. And because the disease is so rare, physicians will often attempt to rule out other conditions first.

As many patients and doctors know, waiting on PBG and porphyrin test results can bring on a tremendous amount of undue suffering for the patient. The TECO test will remove this grueling wait.

Although the test is simple, use of the test kit is limited to trained professionals. If the assay confirms acute porphyria, it is recommended that the patient be further evaluated to define the type.

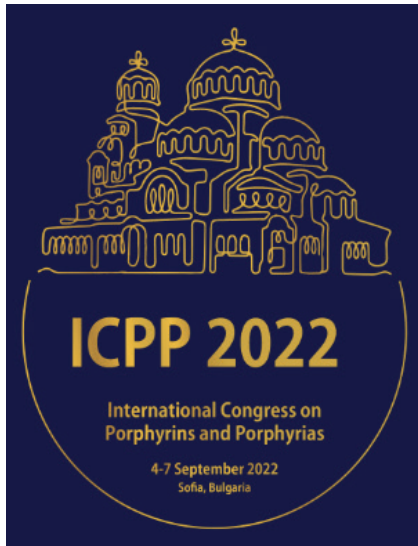
One patient said, "When the hospital told me that I couldn't

get the Panhematin treatment I sorely needed until the PBG test came back, I cried. The pain was excruciating and relentless. Making me wait for treatment was inhumane. This test will prove I am in a porphyria attack."

If you are interested in ordering the Rapid PBG test from TECO, please call 714-463-1111 or visit tecodiagnostics.com. Please tell your hospitals, clinics and doctors about the test. Together, we can make it easier and faster for patients to get a diagnosis.

EVENTS

Join Us For the International Congress on Porphyrins & Porphyrria



The International Congress of Porphyrins and Porphyrrias (ICPP) will take place September 4-7, 2022 in Sofia, Bulgaria. The ICPP will be held at the Grand Hotel Millennium and bring together patients, researchers, experts and scholars for three days of networking and learning from the best in the field. The Congress will cover topics like fundamental and clinical research, best practice of treatment and diagnosis in the service of porphyria patients. Congress organizers have complemented the scientific aspects of the event with social activities, including a city tour of Sofia, which is one of most ancient cities in Europe with history dating back to over 5,000 BC.

The Welcome Reception on September 4th, 2022, will be an exciting gathering where attendees will meet new and old colleagues and friends in an informal atmosphere. The Farewell evening, September 6th, 2022, coincides with the Unification Day, a national holiday in Bulgaria. The hosts have prepared a special evening displaying the customs and traditions from Bulgaria.

In addition to the scientific program there will be two special events to note: Pre-Congress Regional Workshop and Patient Day. The workshop's goal is for diagnostic laboratories to provide physicians with improved guidance on ordering the proper biochemical and genetic diagnostic tests for the different types of porphyria.

Patient Day program will be filled with activities to build camaraderie between patients, patient organizations and physicians. The program includes a report from patient organizations, testimonials from patients about their experience, a role reversal activity between patients and doctors, and other educational presentations.



Dr. Aneta Ivanova,
President of the ICPP 2022

Thank you to Dr. Aneta Ivanova, the President of the ICPP 2022. Despite the repeated COVID postponements, Dr. Ivanova and her team have arranged an outstanding Congress. To view the conference schedule, visit icpp2022.com.

Porphyria on TV

In the past, the APF worked with television series and local news broadcasts to feature porphyria as part of their storyline. This July, we're bringing back this push with the start of a Major Media Project! You can help by contacting local radio and TV stations. Contact the APF for information, quotes and educational materials.

PAST EVENTS

Let's Talk Porphyria!

Nicole Castellano hosted another *Let's Talk Porphyria* virtual event this Awareness Week, focused on porphyria and emotional health. Patients and caregivers discussed coping mechanisms. Interestingly, patients felt guilty relying on caretakers, and caretakers felt guilty being too exhausted to cope. Nicole's honesty in sharing her journey established trust in the group and encouraged people to open up. Everyone agreed they needed each

other, and their pets! Watch for news of the next *Let's Talk Porphyria!*

Nicole poses on the beach with her beloved Vizslas, Laszlo and Mila.



Zoom with Dr. Hapani



Dr. Sanjaykumar Hapani practices hematology/oncology in Oklahoma City. He sees so many porphyria patients, his clinic is dubbed "Porphyria West!"

The APF hosted a porphyria educational zoom with Dr. Sanjay Hapani. ZOOM calls provide an opportunity for patients to learn and ask questions of an expert virtually. The patient attendees expressed their gratitude to Dr. Hapani for his outstanding presentation and his patience in answering an array of questions about their cases.

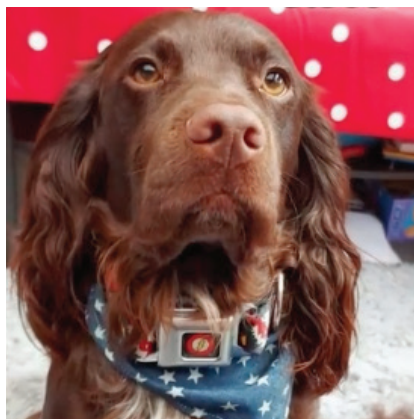
Because he is such an outstanding porphyria expert, patients are now traveling great distances to visit his practice in Oklahoma City. In fact, he has so many porphyria patients, some have named his clinic the "Porphyria West!" Watch the APF website and our seven Facebook groups to learn about the next ZOOM call with Dr. Samuel Silver.

Awareness Week Pet Parade

Porphyria Awareness Week was not only educational but also had fun activities. We held the APF 40th birthday with lots of well-wishers. The APF conducts many activities with pets because pets are key in the healing process. According to the Mayo Clinic, pets have the power to help heal patients experiencing emotional or physical pain. Pet therapy is a growing field that uses animals to help people cope with health problems. That's why we celebrate pets with a Pet Parade! It featured dogs and cats, as well as Dolly the cow, and a bevy of beautiful birds.

Cisco the dog took first place, captivating all with his regal pose. Peaches and Pippy, two love birds rescued by Nanelle Taylor, took second. Thanks to everyone who entered a pet, they are all winners in our eyes!

Cisco took first place in this year's Porphyria Awareness Pet Parade!





CUTANEOUS PORPHYRIA

Coolibar Donates Sun Protective Clothing

Coolibar recently sent the APF a collection of their UPF 50+ sun protection clothing, including hats, face masks and gloves. We, in turn, sent the hats to interested people with CEP and EPP. Coolibar manufactures and markets UPF 50+ sun protection that never washes out of their products for men, women, and children. The company's portfolio of products includes sun protective clothes, SPF clothing, sun hats, sun protection swimwear, sunglasses, umbrellas, and sunscreens.

Founder John Barrowe grew up in Australia. He needed sun protective clothes to shield him from the sun and the ensuing rashes that followed his sun exposure. Most early wearers were surfers, and from there Coolibar grew to become the world leader in UPF 50+ fabric technology.

Interested in purchasing Coolibar? Contact the APF for 20% off coupons and shop at Coolibar.com!



APF staff member Amy Burke, who lives with PCT, rocks her Coolibar hat on a sunny day.



I received my first Scenesse implant for EPP 15 days ago. Since then, I've experienced the sun on my face with no pain; I've been hiking on a warm spring day in the sun; I sat by a creek, in the sun with my feet in the water and no pain! I literally started bawling my eyes out right then and there.

The other hikers would've thought I was crazy!

When I was hiking last week (just 9 days after the implant) it felt unreal like I wasn't in my own body. I asked my 6-year-old, "Is this real?" And he said

"Yes Mama, the sun feels warm and it doesn't

burn you!" Watching him watch me in my joy has been amazing.

I had a minor reaction on day 9 of Scenesse. That night my fingertips and hands felt hot, but it was nothing compared to what I would have felt like prior to the implant. I used to burn within two seconds in the sun. This hike was magic—I was out for 2 hours in mostly sun! Also, I'm definitely still worried about pushing the limits, so no sun bathing on the beach yet.

The Scenesse implant works, I fully understand it's not a cure, but it has given me a new life which brings me to tears.

Margie Rose's Miracle



MARGIE ROSE,
lives with EPP

Thanks to Scenesse, Margie Rose can hike with her family again. Here she is, posing out in the sun!

12 Misconceptions About Porphyria

By Claire Richmond for PorphyriaNews.com



Claire Richmond is a patient columnist for PorphyriaNews.com. She writes about navigating day-to-day challenges with acute porphyria.

Living with porphyria is not easy. But the most difficult part can be managing my inner turmoil when the people in my life who should understand don't even try. While I would never wish porphyria on another human, I frequently find myself wanting my loved ones to magically understand how it feels. I stare down loneliness every day. But as much as it seems like I'm the only one navigating these strange waters, there are people in my life who try to understand. And then there are those who truly do: my friends with porphyria.

For the recent Porphyria Awareness Week, I asked people affected by this disease to share misunderstandings and assumptions their families and friends have. Follows are a dozen misconceptions about porphyria.

1. Pain is visible. "When I get too much sun sometimes, there's no visible rash or crusting, but there's pain. They don't understand what's going on, no matter how much I explain it." — *Darlene, EPP*

2. It's just a heat rash. "They say: 'Oh your son has prickly heat? I get that!'" — *Michelle, EPP caregiver*

3. It's just a sunburn. "They say: 'Oh, I get sunburned too!' I wish that's all it was." — *Kimberly, EPP*

4. Diet and exercise will cure us. "I get lectures on what to eat and advice to slow down because I'm the problem." — *Mayra, AIP*

5. Treatments will cure us. "They think someday I'll recover and this will be behind me. Like, it will be over eventually and things will go back to normal." — *Audra, AIP*

6. We are exaggerating the pain. "They don't understand how bad it can be, and if I'm honest about my pain, all they say is that I complain too much." — *Martina, AIP*

7. We're out of shape. "When I can only walk on the treadmill for five minutes before my legs begin to hurt, or can't do much at one time because of weakness, they think it's because I don't get enough

exercise." — *Jennifer, AIP*

8. We're making it up. "When I try to explain porphyria to them, they think I'm exaggerating. Rather than believing my condition is real, my family and I come across as oddballs." — *Pam, AIP advocate*

9. We're unreliable. "I cannot really plan. I do, and then I may have to cancel. They don't get that it's not under my control." — *Fiona, AIP*

10. We're sick all the time. "The intermittent part of porphyria is hard for them to understand. That is why they've thought I'm faking the bad part." — *Desiree, AIP*

11. It's easy to manage. "It gets minimized and reduced because no one could possibly understand the chronic symptoms unless you live with them." — *Elizabeth, AIP*

12. It's only physical. "They think it only affects my body and not my mental health." — *Jacqueline, AIP*

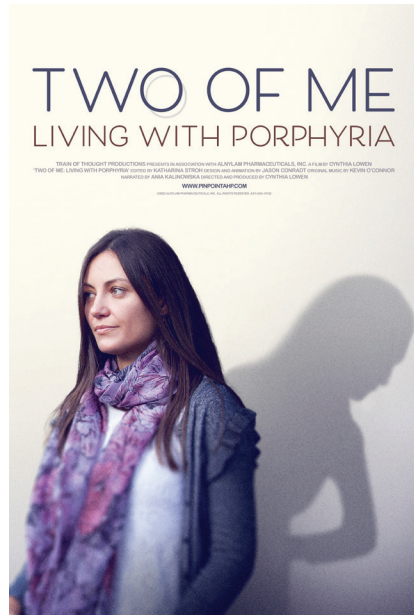
Porphyrias are complex conditions. Until we can swap bodies with others, we simply don't have the energy to spare for people who don't want to understand.

Thank you to PorphyriaNews for allowing the APF to reprint!

ACUTE PORPHYRIA

Porphyria Documentary

Two of Me: Living with Porphyria chronicles the lives of seven people around the world living with acute hepatic porphyria (AHP). It's a story of human strength, perseverance and survival. The documentary highlights common themes those of us living with AHP understand all too well, including the challenges in receiving a diagnosis, the immense physical, mental and emotional toll of the disease, as well as its impact on relationships, careers and aspirations. Check it out on PinpointAHP.com and send the link to your loved ones!



Two of Me: Living with Porphyria chronicles the lives of people living with acute hepatic porphyria. Watch it today on PinpointAHP.com.

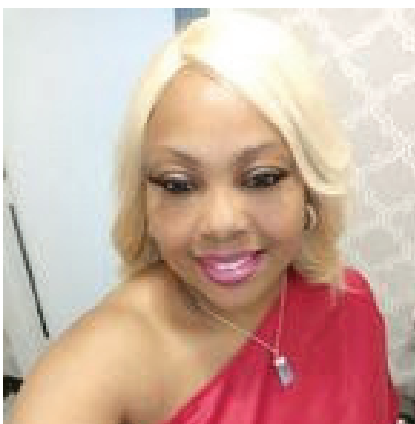
Givlaari Forum

Givlaari, is a new treatment for acute porphyrias given once a month as a subcutaneous injection. Because the experience with the drug is limited, patients wanted a space to share their positive and negative experiences with others taking the drug.

The APF hosted a patient-only Givlaari Forum on May 2, 2022. Twenty patients logged in, while twenty more shared experiences with APF staff. A report of patient comments is being created.

MEMBER PROJECTS

New Member-Led Caretaker Program



Nedra Johnson partners with the APF to support porphyria caregivers.

Nedra Johnson is leading the APF's new caretaking program, and she's perfectly suited for the role. Nedra operates Angel's Touch, a business

that assists people with intellectual and developmental disabilities.

When her daughter Lakeisha started having porphyria attacks, she was already trained to help.

Besides caring for her physically, Nedra handled challenges patients cannot manage alone. On several occasions, Nedra advised providers on the intensity of porphyria pain.

She intervened many times in order for her daughter to gain access to treatment and proper care, becoming acutely aware of

the difficulties that both patients and caretakers face during attacks.

She founded The Mercy Foundation of Texas for people with serious health issues. "There are many opportunities to show mercy in this world," Nedra said. "I want to always be ready to help." She also began talking with porphyria caregivers about needs.

Are you a caregiver for someone with porphyria and need support? Would you like to share caregiving tips, please contact 866-APf -3635.

MEMBER STORIES

Joe Calamia Rides Again!

Every year, Joe Calamia rides his mountain bike on a 700-mile adventure from Detroit, through Ohio and onto Pittsburgh, through the Allegheny Passage to Maryland and, finally, to DC. Joe's biggest challenge is keeping up

the carbohydrates to prevent AIP problems. Fortunately, the attacks have not prevented him from his bike adventures. In fact, during his rides, Joe says he ate 8,000 calories having mostly carbs in the day and protein at night. He loaded

up on gummy worms and fruit pies, stopping at gas stations and restaurants to add French fries and pasta for carbs and hamburgers for protein at night. Joe says living well with AIP requires you know your body, eat carbs and live carefully.

Amalia's Art

Amalia found escape in her art, as she fought through the pain and confusion of unknown illness.

Amalia's paintings, found online, depict her harrowing journey. "I had started college when the first attack came out of nowhere. The pain was unbearable, terrifying

and kept coming. After months of searching, I was diagnosed with an acute porphyria.

I painted myself trying to claw my way back to health but too weighed down, too exhausted. Now, I had a confirmed diagnosis, but the attacks kept coming. When

the doctor mentioned taking Givlaari, I felt like I might have a future with fewer attacks."

Amalia made it through her first semester of school without an attack and now is hope for the tomorrow. Follow along at AmaliasStory.com.

Music with a Mission



EMILY CARMEN,
lives with HCP

Emily Carmen's song "1950s Housewife" will be on video this fall and is streaming now. Support Emily Carmen on EmilyCarmen.com, Instagram and Tiktok @EmilyCarmenMusic, and Twitter@EmilyCarmen.

"Before I was diagnosed, I was severely underweight due to constant debilitating pain that felt broken glass in my abdomen, extreme pain in my arms and legs that made walking even a few feet nearly impossible and fluctuating severely low heart rate that dropped down to 25bpm. Thus, my late teens and twenties were an isolated time in my life. I had to leave my studies in film scoring at Berklee College of Music and was told by doctors that I may never have a "normal life." Nonetheless, I discovered I still could express how devastated I felt through music. I taught myself how to use digital audio workstations to record my songs and played every instrument myself. Songwriting allowed me to have normalcy and to express the frustration of being so scared, socially isolated and lonely with a chronic illness and medical disability. When I realized that there were hardly any performing artists with a chronic illness or disability, I promised when I improved physically, I would become that songwriter and performing artist for others that I had wished for and have as a role model. Thus, I try to make each song relatable.

IMPORTANT NOTICE

Missing mail correspondence with the APF?

Contact 866-APF-3635 or general@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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Best wishes to the class of 2022!

Porphyria challenges didn't stop the following graduates from completing their study:

UNIVERSITY: Miller Polly, Loren Towes, Jeannie and Nicholas Smith, Arriel Rose

HIGH SCHOOL: Claire Predmore, Brianna Colley

REGISTERED NURSE: Missy Ann

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!

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