AMERICAN PORPHYRIA FOUNDATION

2nd Quarter, 2021

We proudly announce the recipients of the 2021 American Porphyria Foundation President's Awards. They honor members and partners who have gone above and beyond to support the foundation or members, and who have served to increase awareness of porphyria.

Jennifer Beck (EPP)

Jennifer has been a visible force for the APF and the porphyria community. From participating on the APF Membership Advisory Board and representing APF as keynote speaker at the NORD Summit opening session to her continual presence on social media, she has championed those with porphyria.

Janie and Jerry Williams

Janie and Jerry have been staunch supporters of the APF's mission for many years. Their support has contributed to the implementation of valuable programs and porphyria awareness. Janie shared that "the foundation has truly been a blessing for both of them!"

Manisha Balwani, M.D.

Dr. Balwani serves on the APF Scientific Advisory Board and is a Professor in the Department of Genetics and Genomic Sciences at the Icahn School of Medicine at Mount Sinai, New York City. In addition, she is an investigator for the NIH-supported Porphyrias Consortium. Dr. Balwani is a tireless supporter of the porphyria community. Her expertise as both a clinician and a researcher have served to advance porphyria patient care and treatment. The APF is very appreciative that Dr. Balwani is beyond generous with her time and talent! Dr. Balwani said, "It's been the most wonderful partnership with the APF and truly rewarding working for the patient community. I look forward to many more years of collaboration."

HEME BIOSYNTHESIS AND THE PORPHYRIAS 2021:

CONSENSUS DIAGNOSES, VARIANT DISORDERS, NEW & EMERGING THERAPIES

It's just around the corner!

SHADOW JUMPERS

The Shadow Jumpers program was created to help give kids with Erythropoietic Protoporphyria (EPP) and their families a place to learn about this rare disease, read tips and tricks learned over time and to hear from fellow kids. Through spreading awareness, fellow EPP interviews, tips for protecting yourself outside and some insight for parents, we hope all families living with EPP will look at this condition as a challenge they can overcome.

A main goal of Shadow Jumpers is to help kids do the things they have always wanted but were prevented by the sun. Pain combined with the emotional discomfort from having to manage this disease may lead kids to avoid certain activities, relationships, and paths in life. Shadow Jumpers wants to remind kids that they can still follow their dreams!

2021 Find Your Shadow Recipients

We're happy to announce our family recipients for 2021's FIND YOUR SHADOW project! This year, we are going to support more families in addition to fulfilling dreams from 2020 delayed due to Covid-19. Shadow Jumpers and the APF can't wait to share dream details and some amazing stories with you as we finish off the year taking down the sun for these FIND YOUR SHADOW recipients!

The Campbell Family
Deagon (6), Mason (12), Braxton (8), Andrea, Brad

The Tonhaeuser Family
Adeline (4), Cole (19), Sophia (12), Kurt Jr (8), Megan, Kurt

The Zamora Family
Anthony (14), Adrian (17), Keyra (4), Avyan (2), Zhianna (2), Adrian Sr, Delena

The Ludwig Family
Cheyenne (10), Riley (8), Ariana (5), Carolyn, Joshua

The Chadwick Family
Madison (9), Isaac (8), Natassja, David

Left to right; Campbell Family, Cheyenne Ludwig, Madison & Isaac Chadwick, Adeline Tonhaeuser, Zamora Family, Tonhaeuser Family, Adeline, Deagon Campbell, Zamora Family, Ludwig Family, Isaac Campbell, Chadwick Family

HEME BIOSYNTHESIS AND THE PORPHYRIAS PLANNED FOR OCTOBER 2021

Scientific Meeting

This 2.5-day educational symposium will feature international and national experts presenting on the latest findings on the biology, transport, and regulation of heme biosynthesis, as well as the clinical features, management, and current and emerging treatments for the acute hepatic and erythropoietic porphyrias.

Meeting Highlights:
» Expert international faculty
» Latest clinical and basic research advances
» Talk tables during breakfast and lunch
» Separate clinical session for patients
» Symposium offers up to 25 CME credits

Register at www.porphyriassymposium.com

You are invited

HEME BIOSYNTHESIS AND THE PORPHYRIAS 2021:
CONSENSUS DIAGNOSES, VARIANT DISORDERS, NEW & EMERGING THERAPIES

OCTOBER 15-17

Hyatt Regency Schaumburg near the Chicago O'Hare Airport

Visit www.porphyriassymposium.com for agenda, hotel information

Is your physician interested in learning more about PORPHRYIA?
Share this invitation to register.

Special Patient Day Meeting

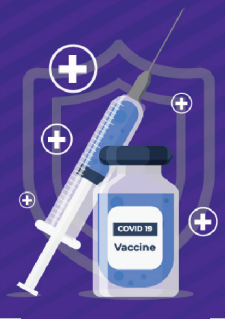
Join us for a special Patient Day Meeting during the Heme Biosynthesis Symposium!

With informational sessions and networking opportunities, this in-person and virtual event is a must-attend for all patients globally. This is an opportunity to learn up-to-date information, get all your questions answered, and to make new acquaintances and friends.

Highlights of the Day Include:
» Latest diagnostic & treatments options
» Educational sessions on each of the eight porphyrias
» The importance of research
» Pain management including the use of cannibis
» Psychological issues and quality of life discussions
» "Ask the Porphyrias Experts" open discussion panel

Don't miss out on this unique opportunity to participate **in-person** or **online** – registration is now open!

Register for the Patient Day Event Now at www.porphyriassymposium.com.



APF'S COVID-19 VACCINE STATEMENT

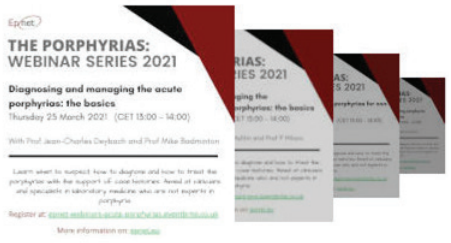
Generally, there is no evidence that any vaccines cause particular problems in people with porphyrias. As a general rule, we therefore recommend that patients with any type of porphyria receive vaccinations in accordance with established guidelines and under the care and follow-up of their personal physicians.

It is the unanimous opinion of the expert physicians of the Porphyrias Consortium that it is important for all porphyria patients to receive the COVID-19 vaccinations, unless their personal physicians have indicated that in their particular medical situations – not including porphyria – vaccination is not recommended.

MORGAN'S STORY

The mission of Sing Me a Story is to serve deserving families in need through the imaginative stories of their children and the power of music. When a child submits a story through a patient organization, it is given to a songwriter who creates a song out of the child's words. Morgan McKillop (EPP, Age 11) submitted a story to the APF that she had written while at home from school recovering from a reaction. "Morgan's Song" was written and recorded by Samara Michael. You can listen here: http://singmeastory.org/stories/morgan-s-story?song=1427

2021 EPNET WEBINAR SERIES



The European Porphyrias Network has hosted a series of webinars over the last several months featuring porphyria experts, aimed at educating medical professionals and specialists in laboratory medicine. The series addressed the acute porphyrias, the erythropoietic protoporphyrias, and porphyria cutanea tarda. The final session is on laboratory diagnosis. Our European colleagues have implemented an excellent series available at https://porphyria.eu/en/content/2021-webinar-series-porphyrias.

ACCURATE INFORMATION STATEMENT

The Global Porphyria Advocacy Coalition (GPAC), with the support of porphyria advocacy organizations around the world and the approval from international clinical and research networks, has produced an important Accurate Information Statement. The statement was created because the global porphyria community is aware of potentially dangerous information being circulated across social media platforms and on various websites regarding the diagnosis, management, and treatment of the porphyrias. Unfortunately, some of the information is inaccurate, misquoted, or taken out of context. Such information could be medically dangerous if taken without input from a porphyria expert or qualified healthcare professional. You can find the full statement (and check out the GPAC website!) here: www.gpac-porphyria.org.

While we are on the topic of social media...

The public APF – American Porphyria Foundation Facebook group just surpassed 4,000 members!!! Up for some time in your online community? You can find the Facebook link on the APF website at www.porphyriafoundation.org.

PHARMA CORNER

ENROLLMENT IN MT-7117 IS FULL!

We are pleased to share that enrollment in the Mitsubishi Tanabe MT-7117 Phase 3 clinical trial to study the investigational drug Dersimelagon in Erythropoietic Protoporphyria (EPP) and X-Linked Porphyria (XLP) is now complete! The study enrolled participants from around the world. A Phase 3 trial is the final clinical trial stage before a potential new drug application is submitted to the FDA.

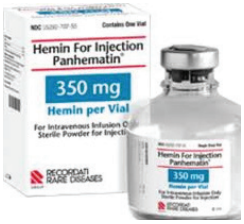
Thank you to all the research heroes who are participating in this clinical trial! Your community is grateful!

Remember ...
Research is the key to your cure!

MITSUBISHI TANABE (MT-7117)
Open Label Extension (OLE) Study

A voluntary open-label extension (OLE) study will be available for participants that complete the ongoing Phase 3 study. An OLE study is a clinical trial that enrols participants of a previous clinical trial and is designed to gather the long-term safety and tolerability data on an investigational drug. Current Phase 3 trial participants interested in possibly continuing their treatment with dersimelagon (MT-7117) are encouraged to refer to their study site for further information.

PANHEMATIN® PREVENTION STUDY



If you are currently receiving prophylactic heme treatment and are interested in participating in the ongoing Panhematin® Prevention Study, please contact Edrin Williams, Director of Patient Services at edrinw@porphyriafoundation.org or 301.347.7166. This research study is important for physicians to better understand the benefits of prophylactic heme treatment. Travel to the study site is included.

Inclusion criteria for the Panhematin® Prevention Study:

» Have well-diagnosed and documented AIP/HCP or VP with lab results;
» Had previous attacks of porphyria with symptoms such as abdominal pain, back or limb pain;
» Currently on a regimen of Panhematin® infusion to prevent acute attacks.

RECORDATI RARE DISEASES GROUP

This year's Recordati Rare Disease/APF Click Campaign was a huge success. For every CLICK, the APF received a $5 donation, up to $5,000 from Recordati Rare Diseases. We are grateful to Recordati for helping us continue our mission to spread porphyria awareness and educate our communities about this rare disease! Thank you to all members, families, physicians, and others who took the time to "click"! Most importantly, thank you for continuing to spread the word about porphyria to your community!

GIVLAARI® NETWORKING FORUM

GIVLAARI® Networking Forum

The APF hosted a patient-only virtual networking forum for members with Acute Hepatic Porphyria who are using the treatment Givlaari®. It was an opportunity for patients to connect in an informal and comfortable group to discuss treatment, share experiences, and to give and get peer support. The APF will be hosting the next session soon. Interested? Please contact the APF at info@porphyriafoundation.org or 866-APF-3635.

RARE DISEASE WEEK 2021

Rare Disease Week on Capitol Hill is an annual event that connects the rare disease community with legislators and fellow advocates. It is an opportunity to educate and spread awareness while advocating for porphyria. While we had hoped to participate in-person, Rare Disease Week will be going virtual for 2021.

Virtual Rare Disease Week on Capitol Hill 2021 will be held July 14-22 and will include the same opportunities as in-person Rare Disease Week, plus more! Go to www.everylifefoundation.org for more information. The APF is in the process of developing a policy one-sheet on legislative issues important to the porphryias. We hope you are interested in joining this important event and will be glad to discuss policy issues one-on-one. Call the APF anytime.

Influence your members of congress by asking them to join the Rare Disease Congressional Caucus in support of those living with rare disease: https://rareadvocates.org/take-action/?vvsrc=%2fcampaigns%2f66800%2frespond

RARE DISEASE DAY AT NIH

Each year, NCATS (National Center for Advanced Translational Sciences) and the NIH Clinical Center sponsor Rare Disease Day at NIH to raise awareness about rare diseases, those affected, and NIH research initiatives. Rare Disease Day takes place worldwide, on or near the last day of February. This year's Rare Disease Day took place virtually. The event still allowed participants to raise awareness among policy makers and the general public by sharing the impact of living with a rare disease. Kristen Wheeden, APF Executive Director, moderated an afternoon session regarding the effects COVID-19 has had on rare disease research. It was a well-attended session that discussed the ways in which physicians, researchers, and patient advocacy groups have been required to pivot in the face of the pandemic to continue research efforts. Over 1,000 participants engaged in Rare Disease Day 2021!

TIME TO PRODROME (TTP)

A Patient Reported Outcome (PRO) in EPP

A new retrospective article was published in Genetics in Medicine using a Patient Reported Outcome (PRO) measure related to Erythropoietic Protoporphyria. The publication "Erythropoietic protoporphyria: time to prodrome, the warning signal to exit sun exposure without pain—a patient-reported outcome efficacy measure" summarized that "Patients with erythropoietic protoporphyria (EPP), a severe painful photodermatosis, experience prodromal sensations when exposed to sunlight, which are the 'warning signals' to exit the sun, as prolonged exposure causes an excruciatingly painful phototoxic attack." The publication can be found at: https://pubmed.ncbi.nlm.nih.gov/33941881.

PORPHYRIAS CONSORTIUM

Pilot & Feasability Program

The Porphyrias Consortium

The Porphyria Consortium is providing a novel support mechanism for U.S. trainees, postdoctorates, and junior faculty interested in pursuing advancements in porphyria.

Support: $30,000 of funding in a single sub-contract to the institution of the applicant.

Please note: Proposed research that falls outside the mission of the Porphyria Consortium will be considered nonresponsive and will not be reviewed. The use of animal models is not permitted.

Program Requirements and Instructions: www.rarediseasesnetwork.org/cms/porphyrias.

VISIT THE APF STORE!

T-SHIRTS, UMBRELLAS, PRINTED SAFE / UNSAFE DRUGE LIST, AND MORE!

PAIN PREVALENCE DATA

A recent study published in the latest issue of the journal Demography highlights the prevalence of chronic pain in the daily lives of individuals. The study suggests "blanket increases across multiple measures, with pain rising in every adult age group, in every demographic group, and at every site of pain for which data exists." The study has shown that societal pain has incrementally increased from one generation to the next. The publication can be found at: www.news-medical.net/news/20210512/Chronic-pain-is-becoming-more-common-in-the-United-States.aspx

More Interesting Reads on Pain:

- https://read.dukeupress.edu/demography/article/58/2/711/168526/Pain-Trends-Among-American-Adults-2002-2018
- www.painnewsnetwork.org/stories/2021/5/12/americans-reporting-more-pain-than-ever

ABSTRACT HIGHLIGHTING PAIN REDUCTION

An abstract presented at the American Academy of Neurology's April virtual annual meeting titled "Reduction in Pain During and Between Attacks in Patients with Acute Hepatic Porphyria Treated with Givosiran: A Post-Hoc Analysis of the Phase 3 ENVISION Study" highlighted trial results from the Phase 3 Trial results of patients with acute porphyria taking GIVLAARI®. The results found that after six months patients found reduced pain during and in between acute attacks.

GIVLAARI® (givosiran) is a prescription medicine used to treat acute hepatic porphyria (AHP) in adults. The abstract can be read at: https://index.mirasmart.com/AAN2021/PDFfiles/AAN2021-001463.html.

A JOURNEY WITH PORPHYRIA – ERYN SALLEE

A few years ago.....

The elevator doors opened, but I did not move. My feet were lead, my face drenched with my own salt, my sobs quiet and wrenching. I was in the middle of a bustling urban hospital. I was sick, in a deep, poisoned, unrecognizable way. I was a 'mystery patient' – despite specialists, tests, and scans, I suffered without a diagnosis. My life was reduced to waiting. Neurology appointment after cardiology appointment. I walked (or was wheeled down) the halls of hospitals, instead of playing at the park with my young children. I went hour to hour in an attempt at survival, exhausted at the prospect of telling my story repeatedly. I felt I had been kidnapped by a serious physical illness. I would find out later just how sick I was.

It was winter. I can't remember what specialist I was dragging myself to, standing in front of an elevator that kept opening and closing, letting people who were crowding, talking, flow past me and disappear into the belly of the building. I remained frozen. Could today be the end of my fight? I remember willing myself to disappear. No one acknowledged my crying, my desperate eyes. Doctors and surgeons on important phone calls hurried past without a glance. Perhaps it was an expected sight, to see a person sobbing. Perhaps they assumed I had lost a family member. But I was losing MYSELF, hope trickling out of me by the second. I thought about sinking into the floor. I was grieving, but not in a way that anyone could know. I wanted it to end.

The doors opened, again, and I willed myself to look up. I remember the people nearby becoming blurry, and I saw only one woman, walking lightly and directly toward me. I was shaking. My nose ran straight into my mouth. I couldn't speak. She approached and she immediately met my eyes, placing her hand on my shoulder, or upper arm – I can't remember. I carry with me to this day the sensation of that touch, the affirmation that I was still a living, breathing being. The affirmation that I was a human in distress and that someone had SEEN me. We held each others' gaze without words and I cried, hard. Somehow we were on the elevator now and she was riding with me, cradling me in her arms.

Elevator Woman whispered "I see you. Cry. I am here." I can't recall her facial features or clothing ... although I can still see the wet, green depths of her eyes as she stared into my trauma and nodded, humbly, acknowledging my pain. It was as if she knew my entire story – that I had been a happy new mother ambushed by a brutal neurological affliction that had stolen everything – eating, sleeping, thinking, walking, breathing, cuddling my babies. But she knew nothing of me. I immediately understood that none of those details mattered. Energy flowed between us and I felt welcome on the earth again.

Years later, I would learn that I suffer from acute hepatic porphyria, a rare metabolic disease. As I write this I am home, snuggling my beautiful daughters. I'm fortunate to have an amazing medical team and treatments for my disease. Today I am back in school, on my long, determined path to help others who are suffering. I will never, EVER forget those few powerful moments when a stranger's loving kindness gave me hope in my darkest hour. Perhaps one day I will step out of the elevator and envelop a person in my arms, murmuring, "I see you. Let yourself cry."

THE APF ACUTE PORPHYRIA ATTACK TRACKER

Keeping track of your acute porphyria attacks and related symptoms will give you a sense of control and allow your physician to help you manage your attacks over time. Your physician can recognize the timing of your attacks, changes to your body, need for treatment, etc. The APF has developed an interactive tracker to help you keep a file of your acute porphyria attacks, symptoms, treatments, and hospitalizations. The tracker is customizable so you can design it to suit your own needs! Go to: https://porphyriafoundation.org/for-patients/support-assistance/acute-porphyria-attack-tracker to access the tracker.

APF EXHIBIT AT DIGESTIVE DISEASE WEEK 2021

DDW Digestive Disease Week®

The APF was one of the exhibitors at this year's Digestive Disease Week 2021: Centered on Growth. This virtual event was held May 21-23. This critical conference is a must for medical professionals working in research, patient care, and education. Digestive Disease Week® (DDW) is the world's largest gathering of physicians, researchers, and industry in the fields of gastroenterology, hepatology, endoscopy and gastrointestinal surgery.

PORPHYRIA DIAGNOSIS DIFFICULTIES ARTICLE

The February 1st edition of the American Society of Hematology's (ASH) Clinical News featured an article on the difficulties of diagnosing porphyria. The article highlights interviews with porphyria clinical experts and covers diagnostic, treatment, and management approaches in the field. The full article can be found at: www.ashclinicalnews.org/education/a-primer-on-porphyrias.

HEPATOCELLULAR CARCINOMA (HCC) AND ACUTE HEPATIC PORPHYRIA

The expert physicians of the Porphyrias Consortium recommend that all patients with Acute Hepatic Porphyria (AHP), regardless of the severity of symptoms, be screened for liver cancer, sometimes called Hepatocellular Carcinoma or HCC. A study titled Hepatocellular Carcinoma in Acute Hepatic Porphyrias: Results from the Longitudinal Study of the U.S. Porphyrias Consortium (https://aasldpubs.onlinelibrary.wiley.com/doi/epdf/10.1002/hep.31460) appeared in Hepatology, a publication of the American Association for Study of Liver Diseases (AASLD) and was recently published online. According to this study of over 300 patients, "1.5% of patients with AHP had HCC." Please note – this study was made possible by patient participation in research! Remember … Research is the Key to Your Cure!

LAURA GALLAGHER (EPP)

My Day in the Sun after Scenesse®

I'm not sure if I have words to describe it because I have no idea what it's going to feel like: To be in the sun without fear, without feeling guarded. To walk a street and instinctively not go to the shady side. To step outside and instantly know if it's a good or bad day and pay no attention because I'm suddenly now capable. It'll be a whole new world. A world I've never dared to imagine. I have lived a sheltered life, literally.

The freedom of just simply being in sunlight is so foreign to me. I wonder how that'll feel.

My vision is brilliant! Carefree, happy. Will it be like that? Could it? Will I actually run down the beach with my daughters as we imagine? They are as excited as I am with this possibility. Will I once again disappoint them? Everyone? Will it be enough? Will I be too scared to try? Will I do too much and screw everything up? Is this really a fix to what I've been dealing with my entire life? God, I hope so.

I hope I feel sun on my feet, face, hands, and arms and I'm anything but petrified or anxious. I hope that I can stand on the ocean's edge and watch my feet sink in the sand without concern watching the sun shine down and not be scared that it will hurt me. I pray that I splash with nothing but smiles and laughter as the tide rolls in and maybe even takes me off balance. I hope so much and dare to imagine more. Too much actually. Too much to even consider. I've thought about this for so long. I pictured a place where I was that person in only dreams. Is that dream actually going to happen? Carefree and happy in the sun? Seriously?

I have lived this way for so long. Guarded, sheltered, hidden. Will I be able to embrace the realization that I'm suddenly now okay? Will I succumb to everything my mind has trained me to avoid my entire life?

I'm super scared, super excited. Oh my gosh! Is this really happening? Going to be possible? Do I dare to picture me, ME, anywhere other than in a cabana, under a tree, indoors watching from a window? Am I actually going to be able to be with everyone else?

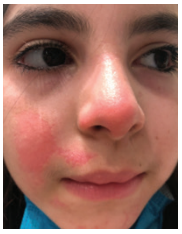
So many emotions. So many concerns. I hope it's all I imagine. I hope I'm capable of embracing it. Knowing no other way for so long has had an effect on everything I am. I'm not sure if I will be able to accept that the sun is now suddenly okay and no longer something that's going to cause me days of pain. An enemy to avoid and now, for the first time, no longer. I'm scared. I'm excited. Totally overwhelmed. But mostly, I'm looking forward to just "being." It's finally here, all I've imagined my entire life. My time is literally just weeks away.

LAURA GALLAGHER RECEIVED HER FIRST SCENESSE® IMPLANT THIS MONTH!

EPP MAMA WARRIOR

Inbal ben Shalom – A Force of Nature and an amazing APF Connection

Inbal, a native Israeli, had never heard of porphyria nor had any family members exhibit symptoms. When her daughter, Maya, began exhibiting a burning sensation on her skin, Inbal began a diligent, six-year search with countless doctors to find the source of Maya's horrendous pain, itching, swelling and sleepless nights. Unfortunately, neither Inbal nor the doctors connected the sun with Maya's terrible illness. Despite the outward signs, some doctors even intimated Maya's problem was primarily psychological – the plight of many porphyria patients. They ultimately decided Maya had allergies and began treatment, but Maya continued to suffer.



Inbal was desperate to help her child, yet the symptoms continued and the wait to see the top geneticist proved impossible, so they were put with a young intern. This was the fortuitous event of their lives. The intern had learned of an episode of "House" that paralleled the child's symptoms and suggested testing Maya. When the results for EPP were returned it was a joyful time for Inbal and Maya – as they had an answer at last. Even more miraculous, the geneticist admitted later that she never would have tested for porphyria had she seen the child.

In her valiant search for treatment, Inbal found that there were many benefits in Israel for children with rare conditions, though they were not known to the public. Inbal has since heightened awareness of these subsidies for other EPP children and those with rare diseases. Israel provides regular medical benefits, gives Maya a caretaker at school and a therapist to help her cope with her EPP. She also was able to acquire therapy for Maya, as well as discounts for electricity, and a host of other opportunities to make life easier for Maya. Inbal subsequently met with Israel's Health Minister and was able to have porphyria deemed a disability "category" to assure access to certain benefits.

Inbal began receiving invitations to speak about EPP at medical conferences and creating videos on the disorder. She is also a primary contact for diagnosed patients with EPP. Ironically, years after the "House" episode, when Desiree Lyon, APF Global Director, and Inbal connected, Desiree shared her responsibility for the story line about porphyria. Both were teary to think that they were connected years before they ever met.

Inbal and Desiree will be collaborating on more ways to advance porphyria awareness in Israel and make life there less challenging for patients. We sincerely appreciate Inbal and welcome her into the APF Global Program as a Global Ambassador.

PORPHYRIA NURSE ADVOCATE VIDEO ON YOUTUBE!

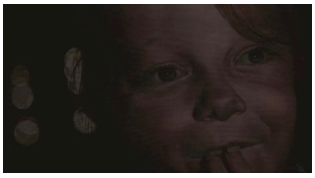
The Porphyria Nurse Advocate (PNA) team created an awareness week video intended to share information with other nursing professionals. The video and initiative titled "Tell 3 More" encouraged nurses to watch the video and share with three other colleagues. The video begins with Chanan Stauffer, NP at Mt. Sinai in NYC. Chanan, under the expertise of porphyria expert Dr. Manisha Balwani, shared detailed information about the porphyrias. Her introduction was followed by other PNA members sharing details and encouraging others to learn and go to www.porphyriafoundation.org for detailed information. Well done, PNA! Please go the the APF channel on YouTube to see this video and many others!

PORPHYRIA CUTANEA TARDA – AWARENESS WEEK STORY!

Chrissy Dirnbeck, R.N.

In preparation for Porphyria Awareness Week, I added the PAW frame to my profile picture on Facebook. Within minutes, my aunt that I was very close to during my childhood commented on my post. This aunt on my mother's side was aware that her mother and one of her sisters, not my mother, had the diagnosis of Poprhyria Cutanea Tarda. She was not aware that I share the same diagnosis with them. I was diagnosed with Type II Familial Porphyria Cutanea Tarda in 1991, just after completing college and beginning my career as a High Risk Labor & Delivery nurse. My other aunt that shared the same diagnosis as me did not have any children. In my aunt's mind, the porphyria had stopped with them and had not been passed on to anyone else. No one else in the rest of our family was ever diagnosed or had shown symptoms of the disease until myself, and my aunt was not aware. This information became very important to her because her daughter was pregnant and expecting her first child in September. After we messaged back and forth just to catch up, I proceeded to share any and all of my medical documents with her. I even had my grandmother's original documents from her initial diagnosis in 1977. She was sorry to hear that I shared in the same diagnosis but grateful that she now knew and had all of our medical documents, including my genetic testing and thorough work-up from Mayo Clinic in 2019.

Social media has often been criticized but in this case, I am grateful that the connection was made. If you are willing to be open and share your diagnosis, it can have an amazing impact in someone's life by giving them an opportunity for an early diagnosis! As we all know, an early diagnosis saves a person years of pain and frustration. Porphyria Awareness Week and Facebook for the win!



APF MEMBER FEATURED IN ART EXHIBIT

APF Shadow Jumper 2019 winner and EPP member Morgan McKillop has earned the very special honor of being one of the latest portrait representatives in the Beyond the Diagnosis art exhibit. Morgan's beautiful portrait, a powerful symbolism of life in the shadows, will join over 100 other rare disease portraits in the exhibit – to be seen by thousands globally!

The focus of Beyond the Diagnosis is on the orphan diseases patient community. With the help of artists donating their skills, the exhibit reaching the goal is to put "a face to all 7,000 orphan diseases." The exhibit travels to medical schools, research institutes and hospitals globally, enticing the medical community to look "beyond the diagnosis to the patient." The museum tour was amazing. The exhibit was at the NIH, FDA, and several other Rare Disease Day events and was seen by thousands of people from around the world. They are already booking the tour for venues for the rest of 2021. The tour is now live on the Artfully Rare website for everyone to watch. Jorgy did an amazing job with the tour and we are so happy. Visit out website at www.artfullyrare.org and scroll to the bottom for the tour.

INTRODUCING JESSICA HUNGATE ... MEDICAL DOCTOR!

Jessica, former APF staff member, remains a wonderful friend to the APF. We are very proud to share that she is now a medical school graduate! Pictured: Jessica and Desiree Lyon

The APF has been members in good standing of NORD – the National Organization for Rare Disorders since it was developed in the early 1980s.

For many years, people with rare diseases walked alone. Patients and their families coped with daunting medical and financial issues with few resources and no one to guide the way. Then, a small group of patient advocates formed a coalition to unify this community and mobilize support to pass the Orphan Drug Act. In 1983, the coalition became NORD, the National Organization for Rare Disorders. For more than 30 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies, advancing medical research, and providing patient and family services for those who need them most.

IN MEMORY & IN HONOR

We thank the familes and friends who memorialized their loved ones with a generous gift to the APF.

IN MEMORY:

Iany McDonald-Schneider for **Carol's Baby, Bailey**; Gary Horn for **Sandra Horn**; Donald John for **Peggy Lewis Johnson**; Aunt Bernice, Mr. & Mrs. Thomas Barletta, Cheryl Manzo, Shelley McGinley for **Alice Kuznicki**; Kathleen Kelahan for **Joan McLean**; Cyndi Nottage for **Natalie Nottage**; Susan Nuckols for **Camden Nuckols**; Michael Bonenfant, Rob, Frances & Elizabeth Daniels, Mary Giudici, KaraRose Gotta, MaryAnne Richardson, Steven Tarolli, Christopher Varley for **Kelli Quenzer**; George Rusnak for **Carol Rusnak**; James Witter for **Barbara Witter**.

IN HONOR:

Paula Andrews for **Hattie & Clint Stuhshatz**; Anonymous for **Amanda Boston's niece – the artist!**, Jesse Lewis Jr., Fran Gandarillas for **Morgan McKillop**; Joan Freedman for **Debbie Redfield**; David & Candy Secrest for **Grace Secrest Shield**; Erin Strunk for **Michael Strunk**; Linda Snow Griffin, PhD. for **Dr. Carl Tishler**; Kevin Vogelpohl & Carmen Ortiz for **Tyler Vogelpohl**; Carole Aitchison, Andrea Bournias, Mollie Darby, Billy Finn, Sharon Wheeden for **Brady Wheeden & the Wheeden Family**; Paige Ernste for **Braden Whiteside** in her residency. *We know there are big things in her future!*

The information contained on the American Porphyria Foundation (APF) Web site or in the APF newsletter is provided for your 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 you consult your physician or local treatment center before pursuing any course of treatment.

What's New at the APF
www.porphyriafoundation.com

Is Your Membership and Contact Info Up to Date? The APF is able to maintain our physician and patient education programs and many other services because of your support. Since we do not receive government funding, we need your support and donations. We also need your new contact information if you have a new address or email. Be sure to send us your email address so you can receive our weekly Porphyria Post.

Our *Protect the Future* program to train future experts is important. Please consider making a donation to this program. Yours and your children's future health depends on each of us supporting the training of doctors who will know how to treat us and perform research when our present experts retire.

DON'T FORGET TO DONATE. YOUR HELP IS NEEDED TO EDUCATE PHYSICIANS AND PATIENTS AND SUPPORT RESEARCH-THE KEY TO YOUR CURE!!!

SUPPORT THE APF TODAY

Your help is needed to educate physicians and patients and to support research. Become a member of the American Porphyria Foundation or make a tax-deductible contribution today.

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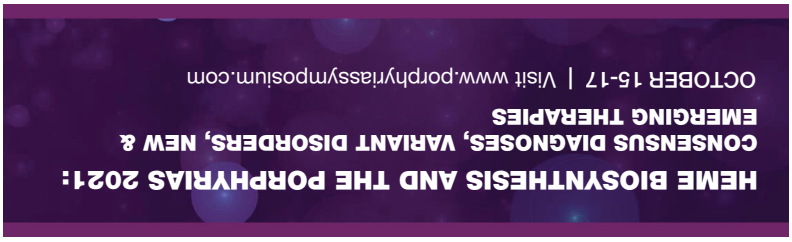

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