



AMERICAN PORPHYRIA FOUNDATION

2nd Quarter, 2020



### President's Award

RECIPIENTS

We are proud to announce the recipients of the American Porphyria Foundation President's Award 2020. The President's award is a time-honored tradition for the APF to honor members and partners who have gone above and beyond to support the foundation or our members, and who have served to increase awareness of porphyria. Congratulations to our 2020 awardees: **CRAIG LEPPERT, MICHAEL BOONE, JORDANNA MORA and BRUCE WANG, MD.**



**CRAIG LEPPERT** Craig was diagnosed with Erythropoietic Protoporphyrria (EPP) at a young age and grew a love for overcoming the sun to do anything and everything outside. That love inspired Craig to partner with the APF to launch Shadow Jumpers – a program to support and encourage children to overcome the sun to do

anything they want. This program is on a third successful year – and Craig's enthusiasm will continue to kindle momentum. As a long-time friend of the APF, we are delighted that he always says YES to research, trials, interviews, articles and being involved in our important work.



**JORDANNA MORA, MS, LCGC, MBA**

Jordanna serves as Director, Patient Advocacy and Engagement, Medical Affairs at Alnylam Pharmaceuticals. Connecting her scientific background in genetics along with her communication and marketing skills, she has commendably engaged with the porphyria

community over the last several years. Jordanna is committed to developing programs that enable Alnylam to truly understand the impact of acute porphyria on patients. Always responsive, beyond caring, with a kind soul and boundless energy, Jordanna is a true champion for porphyria.



**MICHAEL BOONE** Michael Boone was diagnosed with Acute Intermittent Porphyria (AIP) in 2002 after a yearlong battle with attacks. Ever since, he has been both personally involved and a strong proponent for participation in porphyria research. He has been a part of the PC Longitudinal Study, Panhematin study, and the Givosiran clinical trial. Mike also serves a member of the APF

Member Advisory Board. Known as "Michael Aip" on the Facebook pages, he shares information, spreads awareness, and befriends those in need.



**BRUCE WANG, MD**

You may see Dr. Wang as the face of the Porphyrias Consortium (PC) on APF videos, Facebook Live sessions, Q&A responses, Patient Education Meetings or in the media talking about Porphyria. He always says yes to APF requests! We are also proud of his brilliance in the Wang Lab at the University

of California San Francisco and his extensive studies in the Porphyrias. Dr. Wang joined the Porphyrias Consortium as a *Protect the Future* physician. He has embodied the mission of this program to promote the next generation of Porphyria Experts and has become an incredible resource for the APF and patients.



### PATIENT EDUCATION MEETINGS

Due to the COVID-19 pandemic, we were forced to cancel Patient Education Meetings. The APF plans on rescheduling these meetings – the wellbeing of our patient community continues to be our primary mission. We hope to have dates soon for re-scheduled and new meetings. Want to host a meeting? Contact the APF.

### WEBSITE UPDATES

The APF has had many exciting updates to its website – all to bring the latest news and information to our community. Here are the latest additions:

**FAQ** – Responses to the questions were written and evaluated by the expert physicians of the Porphyrias Consortium.

**Glossary of Medical Terms** – Patients may find the glossary helpful when communicating with physicians or advocating on the behalf of porphyria.

**The Purple Light Blog** – Designed for the porphyria community – you will find share tips, stories and self-help measures.

# COVID-19 AND PORPHYRIA

The American Porphyria Foundation will continue to share updates regarding COVID-19 in collaboration with the expert physicians of the Porphyrias Consortium (PC) and our pharmaceutical partners. The APF remains open and available to sup-

port your needs and questions during the COVID-19 pandemic.

The American Porphyria Foundation and the physicians of the Porphyrias Consortium encourage our members and patients to follow the guidelines recommended by the Centers for Disease Control and Prevention (CDC) regarding Coronavirus, which causes COVID-19.

To keep our patient community abreast of developments related to porphyria during the pandemic, the APF created a special page on our website dedicated to

COVID-19. The page contains helpful information and updates from the experts of the Porphyrias Consortium. We will continue to update this page and provide our patient community with the latest information for as long as necessary.

Please note that, in general, patients with porphyrias, unless they also have heart, lung, kidney, or liver disease and/or are receiving immunosuppressive therapy or chemotherapy for non-porphyrin diseases, are NOT at increased risk for contracting COVID-19 infection, nor at increased risk for adverse outcomes if they do.

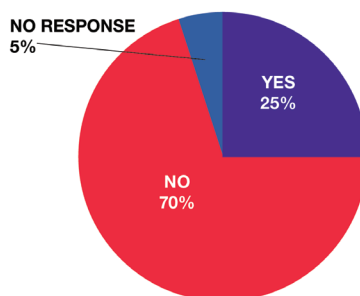
## COVID-19 AND PORPHYRIA: NEEDS ASSESSEMENT

The American Porphyria Foundation (APF) released an assessment regarding the burden that COVID-19 (Coronavirus) is having on our community members. This information has helped to create meaningful and informative programming.

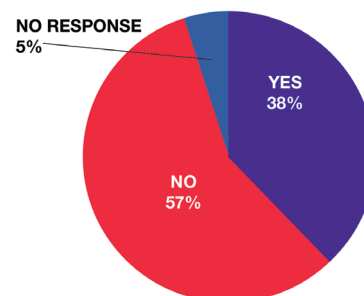
The responses indicate access to care and treatment have been affected, that APF members are adapting to COVID-19 through increased telemedicine appointments, and that emotional/mental health is a primary concern.

We have provided increased support and monitoring of access to treatment and pain medication, offered guidelines recommended by the Porphyrias Consortium for telemedicine appointments, and we are ready to offer a webinar regarding new guidelines for access to treatment. In addition, the APF has regular communication with pharmaceutical partners regarding treatment and we have introduced Porphyria Partners to combat isolation. Complete results can be found here: <https://porphyriafoundation.org/for-patients/covid-19-and-porphyria/needs-assessment>.

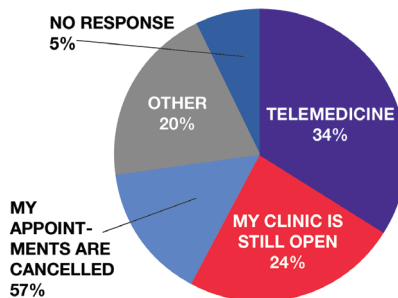
**Have you had trouble gaining access to treatment since this pandemic began? (Panhematin, Givlaari, Pain Medication, etc.)? If yes, please describe below.**



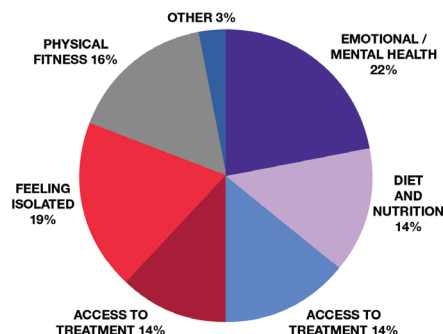
**Do you feel that your medically necessary care has suffered due to COVID-19?**



**How are you managing your medical appointments?**



**Are you willing to share your concerns with the APF regarding porphyria and COVID-19? Select all that apply.**



## TIPS FOR AN EFFECTIVE TELEMEDICINE APPOINTMENT

- 1. Prepare** your smartphone, tablet, or computer ahead of time.
- 2. Set the Scene!** Make sure that your surroundings are clear from any distractions.
- 3. Be Prompt:** Make sure that you are on time for your appointment.
- 4. Be Prepared:** Have your questions ready.
- 5. Take Notes:** Be sure to take notes on your appointment (treatment plans, future appointments, etc.).



## PORPHYRIA PARTNERS

The APF has created a simple way to feel less alone and to connect with others in our community through Porphyria Partners. With no social media as a requirement, we have facilitated patients to patient partnerships. Members become friends who check in with their porphyria warrior partner each day. The APF simply identifies partners and the rest is up to you! Please contact us if you would like a Porphyria Partner match.



## MITSUBISHI TANABE MT-7117 PHASE 3 CLINICAL TRIAL

First Trial to Include Adolescents (Age 12+)



Mitsubishi Tanabe is now screening for a Phase 3 trial for MT-7117 for patients with EPP!

The hard work of those who participated in the Phase 2 trial paved the way for this FIRST clinical trial that includes adolescents.

**Trial Description:** A Phase 3, Global, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate Efficacy, Safety, And Tolerability of MT-7117 in Adults and Adolescents with Erythropoietic Protoporphyrin (EPP) or X-Linked Protoporphyrin (XLP)

**Treatment:** Oral medication (pills), once daily in the morning with or without food  
Duration: 26 weeks plus optional 26 week double-blinded extension.

**Endpoint:** Increased pain free light exposure in adults and adolescents with a history of phototoxic reactions from EPP or XLP.

**Study Sites:** There will be 12 study sites in the US, followed by global study sites across multiple countries.

**Age Range:** Patients age 12-75. Travel will be included and will be arranged by a concierge service trained on EPP/XLP.

Contact the APF on 866-APF-3635 or [info@porphyriafoundation.org](mailto:info@porphyriafoundation.org) for more information. If you have already contacted the APF, we will contact you when your closest study site is ready to open.



## SCENESSE® IN THE US!!

At long last, EPP patients are being treated with SCENESSE® in the United States! April 29th marked the first patients to receive the life-altering implant on US soil. US insurance companies have agreed to reimburse SCENESSE® (afamelanotide) for patients diagnosed with erythropoietic protoporphyria (EPP). Currently, there are four locations that are trained and accredited (by Clinuvel as approved by the FDA) to prescribe and administer SCENESSE®. These centers are in Detroit, MI, Aventura, FL, Los Angeles, CA, and Salem, OR. Following the phased launch, there will be a maximum of thirty treating locations.

### ☑ READY TO GET STARTED?

To access treatment with SCENESSE®, you will need to acquire a unique patient identifier (ID) number and contact an EPP treatment center in the US. Go to [www.scenesse.com](http://www.scenesse.com), select “EPP Savings Program,” and complete the eligibility questions. You will receive an email from Clinuvel requesting documentation and follow-up steps. You will also need to contact a treating location. That location will begin the Prior Authorization process with your insurance provider.

### ☑ THE SCENESSE JOURNEY IN THE US

This was a long and hard-fought battle to bring treatment to US patients. Patient advocacy was KEY to this success. YOU participated in the clinical trials that proved this as a life-altering drug – traveling to study sites and dutifully logging results, even if you received the placebo. Your thousands of letters, dozens of photos, participation in FDA meetings, petitions, and support of Clinuvel in this process were critical. It has been over a decade from the designation as an orphan drug to FDA-approved treatment in the US. The APF is proud of your dedication!

### ☑ TIMELINE

2008 FDA grants Orphan Drug Designation.

2011 Phase 2 Clinical Trial completes.

2013 Phase 3 Clinical Trial completes.

2014 EMA (Europe) grants SCENESSE® Marketing approval for EPP.

2016 FDA holds Scientific Workshop on Erythropoietic Protoporphyrin, including 150 patients and caregivers.

2019 January – FDA grants SCENESSE® Priority Review.

2019 October – FDA approves SCENESSE® (afamelanotide 16mg) to increase pain-free light exposure in adult patients with a history of phototoxic reactions from EPP.

2020 April – First patients in US treated with SCENESSE®.

### HOW IT WORKS

SCENESSE® (pronounced “sen-esse”) acts by increasing the levels of melanin in the skin; and shields against UV radiation (UVR) and sunlight. SCENESSE® is delivered via a subcutaneous dissolving implant approximately the size of a grain of rice. Increased pigmentation of the skin appears after two days and lasts up to two months.

## ALNYLAM ANNOUNCES THAT MORE THAN 50 PATIENTS IN THE U.S. TREATED WITH GIVLAARI



(Alnylam.com, May 6). To learn more about treatment with Givlaari, discuss with your physician and visit [www.givlaari.com](http://www.givlaari.com).



## EPP RESEARCH STUDY

Dr. Amy Dickey, Massachusetts General Hospital, is currently conducting a study that is investigating methods for measuring light exposure and symptoms in EPP. Her study may eventually help patients predict symptoms using a wearable smartphone-based device. This could help patients better manage the disease with reduced anxiety. Patients are answering a brief symptom and light exposure survey every day for two months. For one month, patients will wear a small light sensor. **Please contact the APF at 866-APF-3635, or [info@porphyriafoundation.org](mailto:info@porphyriafoundation.org) for more information and to volunteer.**



## CENTERS FOR MEDICARE AND MEDICAID (CMS) – Temporary Guidelines for Home Infusion/Injection

A new CMS (Centers for Medicare & Medicaid Services) temporary guideline gives acute porphyria patients who are Medicare (Part B and D) beneficiaries the opportunity to receive Panhematin infusions or Givlaari injections at home. The temporary changes were made to ensure that patients have access to care while remaining safely at home adhering to CDC guidelines.

CMS provided two temporary pathways through which patients can receive medical care in their home:

1. Telehealth/Home Health Agency: The treating provider would contract with an entity (home care agency, etc.) to administer Part B drug to patients in their home. If direct physician supervision is required, it would be performed through telemedicine (video, audio or both as needed).
2. Homebound/Home health beneficiaries with conditions that present increased COVID-19 risk: CMS temporarily expanded the definition of “home bound” to include patients w/ heightened risk justifying a “stay home” recommendation. The treating physician would certify that the patient is at heightened risk, including complying with CDC social distancing guidelines.

Please contact your physician to begin the process for this service if you qualify. You can also contact the APF for support.

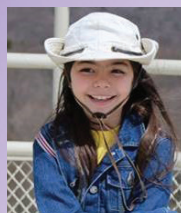


## GLOBAL PROGRAM

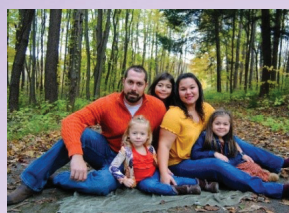
Through the years, patients, and doctors in 76 countries around the world have reached out to the APF for help. Our Global Program not only helps individuals from distant parts of the globe, but also assists people to create patient organizations and support groups. To better assist these groups to grow and become more effective, Desiree Lyon, Global Director, created a comprehensive PowerPoint presentation that features major steps to accomplish that mission in Spanish, Polish, Italian, French, Russian and Portuguese. Also, exceptional articles about porphyria have been translated for these groups and distributed worldwide. When Desiree used Google translate to translate one of the presentations and documents, she was told that she had mistakenly translated porphyria expert as “janitor.” She quickly asked some of the group leaders and industry friends to help translate properly.

Groups are now growing in Mexico, Poland, Russia, Chile, Columbia, Argentina, Pakistan, Sri Lanka, Turkey, and in the Middle East. In this issue, we want to concentrate on the Mexican Society for Porphyria and the wonderful advances they have made.

## SHADOW JUMPERS FIND YOUR SHADOW 2020 RECIPIENTS!



Cheyenne Ludwig (age 9) and the Ludwig family.



Anthony Zamora (age 14) and the Zamora family.



The APF and Shadow Jumpers is pleased to announce the Find Your Shadow Recipients for 2020. Our Congratulations go to two families this year. The Zamora Family and the Ludwig Family will each live out a personal dream experience organized and provided by Shadow Jumpers and the APF. The Zamora Family from Santa Maria, California consists of five children – all living with EPP. Anthony Zamora, age 14, loves theme parks. The one closest to his home, Six Flags Magic Mountain, has always been his most trying. For one reason or another, Anthony has attempted to visit on his own and whether long lines in the sun, issues with protective clothing and more, he has never been able to have the all-day six flags experience his friends have had. The whole Zamora family will enjoy a day of fun shadowing jumping around Magic Mountain (with some added surprises along the way).

Cheyenne Ludwig, age 9, and her family from Pennsylvania plan on fulfilling their dream to shadow jump astride a beautiful black horse. Cheyenne has always had a love for horses and has wanted to ride one since she became a fan of the TV show *Free Rein*, where the main character bonds with her horse. Struggling with adapting to her EPP, the Ludwig family has always hoped getting her daughter to do something she has dreamed about would lead to her adjusting to life with EPP. The Ludwig family will be horsing around at Rocking Horse Ranch in the months to follow.

We look forward to providing dreams come true for these two young Shadow Jumpers and their supportive families!



## APF ONLINE TRANSACTIONS MADE EASY!

Donations and store purchases are now easily done on the APF website. With Visa, MasterCard and now AMEX, transactions are secure and simple. You can even set up an annual recurring donation. We are delighted to offer this simple new platform!

## MAKE A DIFFERENCE FROM HOME

Rare Disease Legislative Advocates (RDLA) staff organizes meetings for rare disease advocates with their Members of Congress and/or staff. The meetings take place in the Representative’s or Senator’s state or district office during the month of August, while Congress is in recess. (Virtual meetings may be held.) For more information, visit [www.RareAcrossAmerica.org](http://www.RareAcrossAmerica.org).

*The APF will prepare you for a Congressional office visit.*

#AskMeAboutPorphyria

# PORPHYRIA



## PORPHYRIA AWARENESS WEEK 2020

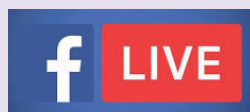
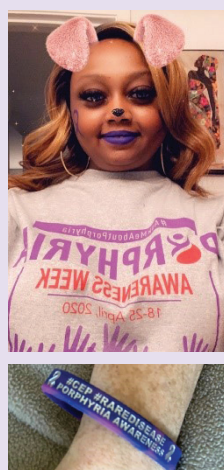
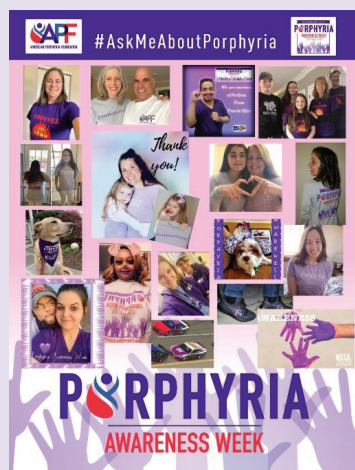
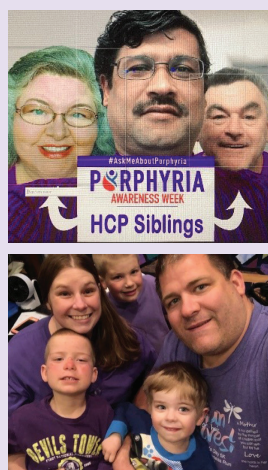
This year, the APF rolled out #ASKMEABOUTPORPHYRIA, a new focus on starting the conversation about porphyria in your communities. Members were encouraged to educate their local communities and healthcare professionals about Porphyria.

Despite many restrictions from the COVID-19 pandemic, we had an active Porphyria Awareness Week! Prior to PAW, the APF sent letters to the Rare Disease Congressional Caucus to support the American Porphyria Foundation, as well as their constituents with Porphyria. We also invited non-members to join the Caucus and invited our patient community to do the same. We were pleased to be informed that the Rare Disease Caucus has 9 new members of the caucus bringing the total membership of the caucus to 170, including 146 Representatives and 24 Senators.

The APF also sent PAW packets out to patients and caretakers who were eager to spread awareness at work and social events. We also had a special spotlight on all the types of porphyria, member stories and a live Facebook session with Dr. Bruce Wang, University of California San Francisco. The week ended with a round-up collage of our wonderful member and supporters sporting purple.

We would like to thank our Rare Disease Congressional Caucus, Dr. Wang, our Pharmaceutical Partners, donors and all our committed members who held events and helped to spread awareness this year.

Even though PAW is over, the conversation and awareness does not have to end. The APF has merchandise available on our website store. Materials are also available from the APF online store and the office for those who wish to continue awareness efforts throughout the year.



### YOUR QUESTIONS... ANSWERED LIVE!

Dr. Bruce Wang, University of California San Francisco, answered your questions during a Facebook Live event on April 22nd during Porphyria Awareness Week. For one hour, patients submitted questions in a live chat session. Dr. Bruce Wang responded, covering topics in each type of porphyria. This session can be accessed in the files of the APF Facebook group. We hope to air another LIVE session soon!

## HEME BIOSYNTHESIS AND THE PORPHYRIAS 2020 – SCIENTIFIC CONFERENCE UPDATE



The APF and Porphyrias Consortium has moved the date of the Heme Biosynthesis and the Porphyrias 2020 – Scientific Conference and Patient Day to October 8-11, 2020. The “Heme Biosynthesis and the Porphyrias 2020: Consensus Diagnoses, Variant Disorders, New & Emerging Therapies”, will be held at the Hyatt Regency Schaumburg - near the Chicago O’Hare Airport. This two-day educational symposium will feature international and national experts who will present 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. In addition to the scientific program, there will be a free patient meeting where physician experts will cover the diagnosis, management, and treatment of the porphyrias and will provide an opportunity for patients to “Ask the Experts”. APF Members can register for the full scientific conference or come to the free patient day! REGISTRATION FOR THE PATIENT DAY IS FREE!



## MEXICAN SOCIETY FOR PORPHYRIA

After suffering with AIP in their family, Kika and her husband, Abraham Shabbot, created the Mexico Society for Porphyria and already have accomplished amazing services for patients, including gaining doctors to treat

patients gratis if needed, as well as psychologists, if needed, to provide emotional assistance. They have communicated with Recordati Rare Disease (Panhematin) and Alnylam Pharmaceuticals (Givlaari) to better understand both treatments for acute porphyrias and join in the struggle to gain treatment access in Mexico. Desiree has acted as a mentor, as has Dr. Juana Ines Navarrete, head of of the Mexican Council of Human Genetics among many other esteemed honors.

In her non-porphyrin life, Kika maintains an already busy schedule teaching yoga and providing patients with yoga therapy and nutritional counseling. She also facilitates annual yoga events in Mexico City where she and Abraham call home but also around the country. In addition, she manages the Mexico City office of Dorfman Kinesiology. Kika is the epitome of the adage, "Ask a busy person" to take on a hard task.

Abraham is the VP and Latin American General Manager of Innophos, a large phosphoric acid company. Because he has seen the suffering AIP caused in his family, Abraham has faced the disease head-on and joined Kika in projects to enhance porphyria awareness and education in Mexico. Abraham's service is far reaching as he is also instrumental in GPAC, the Global Porphyria Advocacy Coalition. If you are interested in Mexico Society for Porphyria, please contact [akshabot@gmail.com](mailto:akshabot@gmail.com).



## IT'S A GOOD IDEA! Incandescent Lightbulb Drive

Are you ready to help our CEP porphyria family? In this time of increased energy efficiency with LED light bulbs, patients with CEP are suffering. CEP damage is activated by all types of light that emit UV, especially LED. The safest light for those with CEP is incandescent light. Incandescent light bulbs DO NOT emit any UV, as they emit UVA rays. The issue is that these bulbs are increasingly difficult to find in stores with the move toward energy efficiency. If you have any extra incandescent lights in your home or see them in a store - the APF will collect them from you and distribute the bulbs to our members with CEP. Please email [info@porphyriafoundation.org](mailto:info@porphyriafoundation.org) for a shipping destination. Thank you for your action that will have a big impact for your porphyria community friends.



## MY PAIN STORY – WITH DR. VANILA SINGH

The American Porphyria Foundation (APF) has had the pleasure of working with the Department of Health and Human Services US Inter-Agency Task Force on Pain. Dr. Vanila Singh, MD (pictured on the left), led this congressionally-mandated program from 2017-2019. Formerly the Chief Medical Officer for the Department of Health and Human Services, Dr. Singh is also an anesthesiologist and pain management specialist with Stanford Health in California. Acute porphyria patient members, Michael Boone (AIP), Terri Witter (AIP) and Sean Albright (VP) had the opportunity to share their experiences with Dr. Singh about managing pain and the use of pain medication via Zoom. This call was facilitated by Kristen Wheeden, APF Executive Director. The purpose of this call

was for Dr. Singh to hear directly from patients with acute porphyria and connect the horrific pain of an acute porphyria attack with the restriction for use of opioid treatment's based on safety in acute porphyria. The stories were distributed by Dr. Singh during porphyria awareness week! We appreciate Dr. Singh's time and effort put toward this program. Follow the link below to review the final report submitted: <https://www.hhs.gov/sites/default/files/pain-mgmt-best-practices-draft-final-report-05062019.pdf>

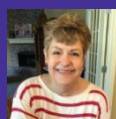
"The fact that people feel stigmatized and feel the need to write that they are not drug seekers is unacceptable in all that I have been trained in." – Dr. Vanila Singh

Below are excerpts from their stories submitted to Dr. Singh:

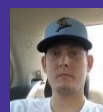


**Michael Boone (AIP):** "By August of 2014, I could no longer work as I was on pain medication all the time. On a good day, my hands and feet ached, my abdomen felt like it had hot coals sitting in it. On a bad day, I wanted to cut off my hands, my abdomen felt as though I was being stabbed with a hot knife, my chest burned with what felt like severe heartburn and, my ribs felt as

*though they were being filleted and then being cut into with a scalpel and unrolled."*



**Terri Witter (AIP):** "When I describe the pain to others, I ask them to imagine walking around with an abdomen full of broken glass or having someone break a glass pop bottle, shove it in to their abdomen and continuously grind it in."



**Sean Albright (VP):** "Sometimes the only way I'm able to do activities such as going to dinner with friends is by taking pain medicine otherwise, I'd be in so much pain I'd be unable to eat. It is an unfortunate fact of life that I'm almost always in pain and pain medication is the only way my pain will lessen to a level that allows me to function."



## PORPHYRIA ART EXHIBIT AT NIH

Select pieces from the *Beyond the Visible* exhibition, visual suggestions and stories about Acute Hepatic Porphyria, were on display at NIH on February 28. Thank you to Alnylam Pharmaceuticals for putting porphyria front and center to all who attended. This exhibit received enormous attention throughout the event. Pictured (L to R): Claire Richmond, Candace Johnson, Anne Jacobs, Kristen Wheeden and Edrin Williams at Rare Disease Day at NIH.



## MEMBER STORY: ARIELLE DIMINO (NORRISTOWN, PA)

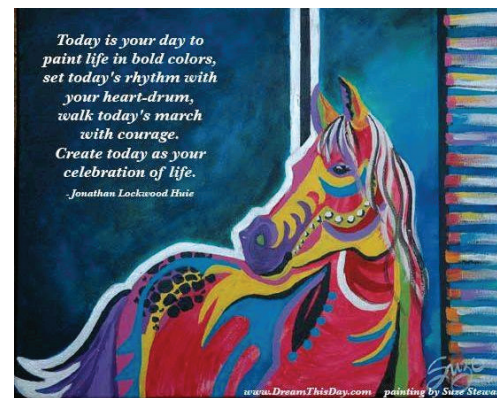
Where to begin? I was diagnosed with Variegate Porphyria (VP) in July of 2019. Prior to being diagnosed I went through four months of being in and out of the hospital with the most excruciating stomach pain and debilitating nausea I have ever experienced. I was beginning to feel hopeless every time I would leave the hospital without answers. After countless tests, procedures, hospital stays and misdiagnoses from other hospitals, Bryn Mawr Hospital was able to diagnose me through a twenty-four-hour urine test.

After months of being poked, my veins started to collapse, and scar tissue began to form. I had PICC line after PICC line and finally my Hematologist spoke to me about getting a port. There was no question in my mind that this was needed. To say I was petrified would be an understatement. I tossed and turned all night the night before and felt like I could get sick at any moment. I went in the morning not knowing what to expect. The procedure lasted about 30-40 minutes and was so easy! I made myself overly nervous for nothing.

Getting a port was the best decision I made. I currently go twice a week for Panhematin treatments. Having a port has been life changing for me. Although I still feel a little pinch at each treatment, it is nowhere near as invasive as before. The first time using the port was intimidating and scary, but now I know what to expect. It is a piece of cake! I have developed such an incredible relationship with my nurse and am so comfortable with her. I am thankful that I was given this life changing procedure and that I can get my medication so easily. If you are contemplating getting a port, please do your research to understand the amazing benefits.


## APF'S OLDEST KNOWN MEMBER – JOSEPH HOSS


Joseph Hoss, 81, from Jacksonville, FL is APF's oldest known member. He was diagnosed at the age of 33, in Birmingham, Alabama. Shortly before that, his mother had also been diagnosed with porphyria by a world-renowned physician in the area. We now suspect that he was referring to Dr. Joseph Bloomer (retired – UAB). Like so many, Joseph's path to a diagnosis was not an easy one. He suffered unimaginable pain and bouts of loss of consciousness. His suffering culminated in being admitted to a psychiatric ward. Eventually, Joseph was diagnosed with Acute Intermittent Porphyria. Despite his many years of hopelessness, Joseph has persevered and survived. His longevity is a testament to his will and though he suffered for many years, Joseph now proudly wears the badge of our longest porphyria survivor! *Mr. Hoss lives alone in Jacksonville and continues to support the APF by donating whenever he can.*



## FAREWELL, MICHELLE SUIA

APF friend and member, Michelle Suita, passed away during a double liver and kidney transplant on April 11. Michelle lived with Acute Intermittent Porphyria. This image was posted by her in late 2019.

 **DONATE TO THE APF TODAY!**  
[porphyriafoundation.org](http://porphyriafoundation.org) or  
 1-866-APF-3635

**READ THE PURPLE LIGHT BLOG**   
[blog.porphyriafoundation.org](http://blog.porphyriafoundation.org)

## IN MEMORY & IN HONOR

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

### IN MEMORY:

Catherin Huffman for **R.B. Brooks**; Lisa Kancsar for **Stephen Kancsar**; George Rusnak for **Carol Rusnak**; Alan Stewart for **Claudia Rutkukas**; Tina Seifert for **Beth Ann Slocum**; Kenneth & Carole Aitchison, Anonymous, Jill Bella, Naomi & Jerry Barsky, Ken Bodmer, Gary & Mary Brewer, Josephine Campbell, Rebecca Carlisle, Sagun Chamillo, Stephen Creyke, JoNell & Mike Dann, Ann H Hunt, Judy & Bill Geoghegan, Janet Hartman, Kristen Kopko, Feng Luo, Richard Lyons, Miles River Yacht Club, Alicia Rasnic for **Dr.**

**Richard Wheeden**; Michael Brown, Teresa Witter, Roger & Kathy Veal, Maurice Yordy for **Barbara Witter**.

### IN HONOR:

Mary Ellen Knop for **Candace Colbert**; Dan & Wanda Foster for **Brett Foster**; Donald & Linda Green Johnson for **Peggy Lewis Johnson**; Catherin Huffman for **R.B. Brooks**; Sharon Koch for **Debbie & Adam Lotterman**; Anonymous (2), Athearn Family, Aunt Joan, Aunt Kathy & Muriel, B-Dad, Anne Marie Balzer, The Barrett Family, Cathy Cimato, Cassidy Clark, Rob Cosentino, Amy Dickey, Charlyn DiLorenzo, The Garafola Family, Debbi Hole, The Hunter Family, Jason, Becca, Jacob and Chloe, Julie, John Kiesel, Omi & G, Dan-

iela McKee, John LaMere, Michelle Labuski, The Margolis Family, Brooke Mattimore, Nyree Meadows, Pam Moore, Patricia Nelson, Maureen Oro, Jen Pinto, Joanne Pirrone, Kelly Rini, Jeannine Roberts, Jennifer Robertson, Jeanne Rohena, Suzette, Laura, Mike, Gwen, Nate, and Bri Thompson, The Trotta Family, Robin Weisberg, Brady Wheeden, Dawn Whitmarsh, Edrin Williams, The Wuestmann Family, Matt & Tricia Zeitler for **Morgan McKillop**; Lisa Kancsar for **Rosalie Nielsen**; Matthew Williams for **Jaqueline H. Rector**; George Rusnak for **Carol Rusnak**; Tom & Elaine Smuczynski for **The Smuczynski Family**; Donna McGlaughlin for **Kristen Steinhilber**; Shanice Thakur for **Amber Whitmore**; Robert & Barbara Fielitz for **Savanna Wingard**; Kenneth Johnson for **Anonymous**.

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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.

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## RARE DISEASE WEEK 2020

Rare Disease Legislative Advocates (RDLA), a program of the EveryLife Foundation for Rare Diseases, brought together over 900 patients, caregivers, and others in Washington, DC, for a week of events dedicated to empowering patients, families, friends, and healthcare professionals to become legislative advocates. During the week of February 25-28, 2020, rare disease advocates had an opportunity to meet with Members of Congress and to learn about policy updates and best practices for successful advocacy. These events included attending the Legislative Conference, Rare Disease Day at NIH, Hill visits, Rare Disease Day at the FDA, documentary screening and rare disease social gatherings and meet-ups.



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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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