



AMERICAN PORPHYRIA FOUNDATION

2nd Quarter, 2018

## THE AMERICAN PORPHYRIA FOUNDATION HAS A NEW HOME!

**Effective June 1, the APF office has re-located to Bethesda, MD.** Houston has been a wonderful home for the past thirty-seven years - and we are now making a move to the nation's capital. The location will be moments from the National Institutes of Health, the FDA, Capitol Hill, and national rare disease organizations. What won't change? – our toll-free number, our staff and our relentless focus on awareness, advocacy, and research to support all patients and families who are impacted by porphyria.



Each year, the American Porphyria Foundation selects a recipient who has gone above and beyond in support of our foundation and the porphyria patient community. We are proud to present the following individuals with the **PRESIDENT'S AWARD 2018. CONGRATULATIONS TO....**



**NICOLE CASTELLANO** Nicole is a champion for people who live with porphyria. She is exemplary at managing a difficult disease with a can-do attitude – not only for herself, but by encouraging others. Nicole trained and ran the Chicago Marathon, never an easy task, let alone while managing AIP. She used the experience to raise funds for the APF – and every step of her training was filled with honesty and awareness (and videos!) about the burden of living

with AIP. Thank you, Nicole, for all you have done to educate others and raise awareness!



**JARED ULMER** You may know him as Porphyria J! Jared has used his artistic talent and lively sense of humor to create the Porphyria J video series (vlog), focused on creating community and awareness around Porphyria. Available on the APF YouTube channel, each video focuses on a different area of living with EPP – What is Porphyria? A Day in My EPP Life! Not Alone. Travelling with EPP...and many more. Jared also ran the Super Spartan Race – of

course, he archived that experience! Thank you, Jared - we look forward to where your creativity takes you next. Until then, "SEEK SHADE AND STAY HAPPY!"

## ACCESS TO PANHEMATIN®



Last year, Recordati Rare Diseases, Inc. launched the 350-mg single-vial dosage of Panhematin for the improvement of recurring attacks of the acute porphyrias. The single vial 350-mg dosage strength has made treatment of this devastating and painful disease more manageable,

addressing the needs of patients and physicians. We thank Recordati for being responsive to patient needs by increasing the contents of the vial. Panhematin is the only FDA-approved drug for the treatment of acute porphyrias, (acute intermittent porphyria (AIP), hereditary coproporphyria (HCP), variegate porphyria (VP), and the ultra-rare aminolevulinic acid dehydratase porphyria (ADP). It was also the first Orphan Drug and has been used effectively for three decades to ameliorate attacks of the acute porphyrias. HOWEVER, some patients have reported to the APF that they are having difficulty accessing Panhematin treatment. A few of the reasons include: the physician is not ordering this treatment, low supply, long wait to receive treatment, Medicaid or Medicare refusing to pay, patient must be treated only in hospital, and patient can only be treated outpatient. Most of these issues are easily overcome or are simply not accurate. Panhematin will arrive at your clinic or hospital within 16 hours and potentially earlier in emergencies. If you have had difficulty of any kind receiving this treatment, please contact the APF on 866-APF-3635. We will help you contact the assistance program to help ensure access to this life-saving treatment.



## INTRODUCING DR. QUIGLEY, NEW *PROTECT THE FUTURE* PHYSICIAN



Please extend a warm APF welcome to our most recent *Protect the Future* addition, Dr. John Quigley. Dr. Quigley has been in practice for over 32 years. Located in Chicago, Illinois, he specializes in Hematology and Medical Oncology. He is affiliated with University of Illinois Hospital Health & Science Center. Dr. Quigley graduated from the Univ Coll of Dublin, Nat'l Univ of Ireland, Fac of Med, Dublin, Ireland in 1986.

Though already an astute physician with knowledge of porphyria, Dr. Quigley will train specifically in all porphyrias under the guidance of the Porphyrias Consortium. Dr. Quigley's laboratory seeks to explore the importance of heme biology, especially cellular heme transport. At present they are focused on two aspects of this large field. He is accepting diagnosed patients in his practice for treatment and management. Please call the APF for contact information.

## PROTECT THE FUTURE IS A TOP INITIATIVE OF THE AMERICAN PORPHYRIA FOUNDATION!

Training our next generation of Porphyria Experts is critical for new treatments... and a potential cure for our group of rare diseases. Each year, the American Porphyria Foundation funds multiple physicians to become our next experts in all porphyrias.

**Contact the APF to donate directly to the *Protect the Future* fund!**

## CLINICAL TRIAL NEWS



**Clinical trial participants are now needed for two clinical trials. Please see the information below, then contact the APF for more information on 1-866-APF-3635.**

### ERYTHROPOIETIC PROTOPORPHYRIA (EPP) – NEW TRIAL

**PHASE 2 CLINICAL TRIAL** A Phase 2 clinical trial has been initiated to study a treatment for the prevention of phototoxicity in subjects with Erythropoietic Protoporphyrin (EPP). This is a multi-center, randomized, double-blind, placebo-controlled study to evaluate efficacy, safety, and tolerability of MT-7117 in subjects with EPP. This study is sponsored by Mitsubishi Tanabe Pharma Development America. Study Locations: Texas, New York, California, North Carolina, Miami, Utah and Alabama.

### ACUTE HEPATIC PORPHYRIA (Including AIP, HCP, VP, and ADP)

**PHASE 3 CLINICAL TRIAL** A phase 3 clinical trial is underway to study the efficacy and safety of Givosiran (ALN-AS1) in patients with Acute Hepatic Porphyria. This is a randomized, double-blind, placebo-controlled, multi-center study with an open-label extension to evaluate the efficacy and safety of Givosiran in patients with Acute Hepatic Porphyria. This study is sponsored by Alnylam Pharmaceuticals.

### WHAT IS A CLINICAL TRIAL?

Clinical trials play a critical role in helping researchers find ways to slow, treat or even cure diseases. Participating in a clinical trial is a decision between you and your healthcare professional – taking into consideration your health, personal benefits, community benefits and the chance to guide better research. A study involves a protocol (written description of the plan) and Inclusion/Exclusion Criteria (required factors to participate). There are five phases of clinical trials that answer different questions: 0- Exploration 1- Is it safe? 2- Does it work? 3- Is it better than what we have? 4- What else do we need to know? (safety updates) You will be asked to sign an Informed Consent – your permission to include you in the study.

## WARNING! I HAVE ERYTHROPOIETIC PROTOPORPHYRIA



The APF is excited to begin distribution of a warning card for EPP. We have developed a business card-sized warning that will fit in your wallet and shares important information related to a diagnosis of Erythropoietic Protoporphyrin. Cards specific to acute members have been supplied for many years which has saved valuable time and energy in situations where a quick explanation is medically necessary. We are pleased to now offer this to members with EPP. **CALL THE APF TO RECEIVE YOUR CARD 1-866-APF-3635.**



### WARNING!

I have Erythropoietic Protoporphyrin (EPP)

CONTACT APF TOLL-FREE:

1-866-APF-3635 | [www.porphyrifoundation.org](http://www.porphyrifoundation.org)



#spreadtheword

spread the **WORD**  
**PORPHYRIA**  
**AWARENESS WEEK**

April 21-28, 2018

#PAW2018

**We had an ACTIVE Porphyria Awareness Week! Thank you to all – including our international friends – for raising awareness in YOUR communities.** We are grateful to each one of our members

who participated in raising awareness!!! The APF wrote daily articles, blogs and facts about porphyria that were sent out to members via the website, e-news and Facebook groups.

But it is **YOU** who made the difference! In social media and online we reached thousands. Over 23,000 people visited the APF website during the week. 5,888 people read the Purple Light Blog, and there were over 20 thousand views on Facebook! Almost 200 profile pictures were changed to showcase the PAW banner.

Our industry partners got in on the awareness action as well. Recordati Rare Diseases Inc. created a CLICK campaign – 2,000 clicks later raised fantastic awareness and visits to the APF website. Clinuvel Pharmaceuticals launched a social media campaign focused on the burden of living with EPP. Alynlyam Pharmaceuticals hosted an in-house session on Acute Hepatic Porphyria – all staff wore purple for the day.

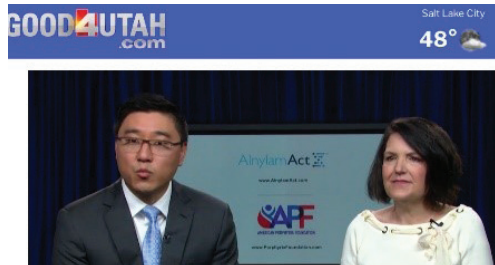
Countless members raised awareness through conversations, activities, fundraisers and more!! Leann Cook held a raffle at a local store for a donated Yeti cooler with signage about porphyria. Griffin's sixth grade class all wore purple to honor and remember

his mom. Louise Schlosser Braun hosted table full of APF brochures at a local hospital to train Emergency Room staff and interns. Allison Stuhlsatz wrote for her local blog, the Wichita Moms Blog. Justin and Holly

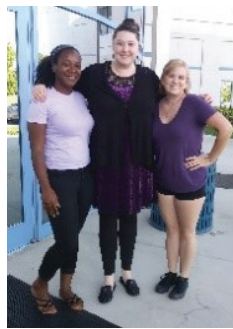
Hamilton were featured in their local newspaper, the Wauneta Breeze, about living with CEP. Dr. Bruce Wang (Porphyria Expert, UCSF) and Mary Schloetter did 17 back-to-back satellite media interviews – all which were written or shared in newspapers and local media across the country. Jared Ulmer, EPP, videoed a visit to a middle school science class where he taught them about his genetic condition. Jenna Steel, age 17, created a video about living with EPP. Morgan McKillop, age 8, was featured in a short film about living with a photosensitive condition. Jennifer Beck's sister held a fundraising event at her workplace. Dr. Amy Dickey, EPP, held a birthday/awareness fundraising event on Facebook. Sharon Dill (VP) created a short video about living with porphyria – it was distributed to family and friends to raise awareness about the everyday burden. A student at Eastern Florida State College, Charissa Strandberg, completed a genetics project on porphyria presented to her class (wearing purple!) along with brochures.

The last day of #PAW2018 was **WEAR PURPLE FOR PORPHYRIA** – dozens posted images! This week was for YOU, APF members, and you did an outstanding job!

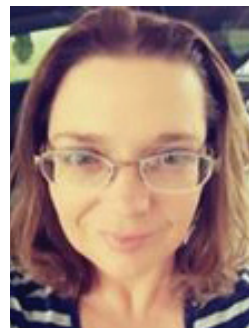
**PORPHYRIA IN THE PRESS!**



Dr. Bruce Wang (Porphyria Expert, UCSF) and Mary Schloetter (AIP) completed seventeen back-to-back interviews with a variety of media outlets during a satellite media tour early morning during Porphyria Awareness Week, which was arranged by Alynlyam Pharmaceuticals. Their interview series focused on the burden of living with an acute hepatic porphyria and the enormous need for physician awareness. The combination of an expert physician and a passionate patient advocate was effective as all seventeen interviews were picked up and distributed by local news outlets. All interviews can be viewed at [www.porphyrifoundation.org](http://www.porphyrifoundation.org).



Charissa Strandberg



Kimberly Dawn Merrill



Amy Chapman and Monica Fleegel



Yail Rosado



Audrey Schering



Sean Albright



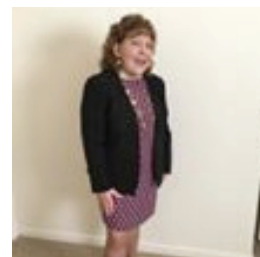
Cassie Tucker and Brenda Kopittke



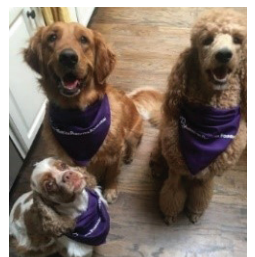
Edrin Williams and Yvette Strange



Justin and Holly Hamilton's daughter



Jessica Melton



Gracie, Springer and Duchess #PAW



# LIGHT THE MOMENT 2018



The Shadow Jumpers team received amazing applications for an all-inclusive Disney experience. The process of selecting one family was extremely difficult as every child who lives with EPP is important to us. We are thrilled to announce the recipient of Light the Moment 2018 – **The Stuhlsatz Family! Ben, Allison, Clint (6), Hattie (4), and Blair Stuhlsatz (6 months)** are headed to Disney World this summer!! Both Clint and Hattie were diagnosed with EPP just last year. The Shadow Jumpers team is working hard to offer them a safe experience of a lifetime at the happiest place on earth. Through spreading awareness, fellow EPP testimonials, tips to protecting yourself outside and some insight for parents, we hope all families with EPP will soon look at the sun as a challenge they can overcome...even at Disney! To learn more visit [www.porphyrifoundation.org/shadowjumpers](http://www.porphyrifoundation.org/shadowjumpers).

## PAIN



People don't enjoy hearing that porphyria pain is worse than any pain they have endured, BUT IT IS! Whether it is neuropathic pain of the acute porphyrias or searing EPP pain, the pain is intractable, immobilizing and agonizing beyond description.



Porphyria does not fit into the mainstream idea of pain, like broken bones, childbirth, muscle spasms or second-degree burns. People have described their pain as “a thousand flaming swords, putting my hand in boiling water, a lava eruption of glass.” But when such a description is given to physicians and even family members, their thoughts then focus on “drug seeker, hypochondriac, pathetic weakling, self-centered.”

Worse yet is when people try to tell you to “gut up, use your inner strength, stop taking pain medications because you will become addicted.” Some people have been faced with one demeaning, belittling remark after another.

What should you do if this occurs to you in a medical setting? Immediately contact the hospital social worker to make sure their remarks do NOT appear in your medical record. Having a doctor write “drug seeker” in your record can be very damaging and is hard to have removed. Ask to see — as soon as possible — what the doctor has written in your record and make sure it is not derogatory. You must have the courage to be your own best medical advocate. Contact the APF if you would like help.

## PAIN PROJECT



**YOUR** pain story is important to the APF and your porphyria community to further our advocacy effort. If you are having issues with your pain, seeking pain management, denial of effective treatment – we would like to hear from you. It does not need to be long or formal – we want to hear and understand your story. Spend a few minutes to help us help you! Please send your story to Edrin Williams, Director of Patient Services, at [edrinw@porphyrifoundation.org](mailto:edrinw@porphyrifoundation.org).



## PORPHYRIA CUTANEA TARDA (PCT) TRIALS – PARTICIPANTS NEEDED



An ongoing clinical trial for PCT is studying an intervention or treatment. In this study all patients with PCT will be given a standard dose of Harvoni and will be monitored for two years. Harvoni is a prescription drug used to treat adults with chronic Hepatitis C. Currently, there are two standard therapies for PCT, phlebotomies (removing certain amounts of blood at specific intervals) or low dose hydroxychloroquine (an oral pill). These treatments are used for patients with PCT whether or not they also have Hepatitis C Virus. For patients with HC, we do not know whether treating the HCV first will also resolve the PCT symptoms.

An initial visit will determine eligibility. If a participant is found to be eligible, he/she will be asked to come to the study site monthly for one year, then every 3 months for another year, to visit doctors and provide blood and urine samples. Lab tests done as a part of this study alone are free. All participants will receive the Harvoni pills at no cost. This is a wonderful opportunity for you to not only change your health, but to help change the health of others with PCT.

**To be eligible, you must:** have a biochemical diagnosis of Porphyria Cutanea Tarda (PCT), have the typical symptoms of PCT (blistering in response to sun exposure, fragile skin, etc.), must have Hep C, be at least 18 years old, and be willing to take an effective method of contraception if you are a female of child-bearing potential.

## TEDx TALK BY SUE BURRELL, BRITISH PORPHYRIA ASSOCIATION



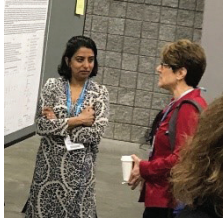
Living with Acute Intermittent Porphyria, Sue is much more than her chronic illness. Her positive ‘can-do’ attitude is not only a self-motivator, but also inspires those around her. Tune into her talk delivered at TEDx University of East Anglia to get a glimpse into what it is to live with this chronic disease, AIP. She works closely with the British Porphyria Association and finds fulfillment in giving back to society. This talk was given at a TEDx event using the TED conference format but independently organized by a local community. See her full talk at: <https://www.youtube.com/watch?v=8uHdArMPpVs>

# COALITION OF PATIENT ADVOCACY GROUPS (CPAG) ANNUAL MEETING



NIH's RDCRN of NCATS held its annual CPAG meeting – What does this all mean and why is it important to porphyria?? The Rare Disease Clinical Research Network (RDCRN) is part of the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health (NIH). This group provides funding to implement research on rare disease – including the Porphyrrias Consortium (<https://www.rarediseasesnetwork.org/cms/porphyrias>). As the patient advocacy group for porphyria, we are a vital member of this group. This meeting allowed our input on operations, activities and strategy. It also offered the opportunity to engage with other patient advocacy groups to work together toward common goals.

## ACMG EXHIBIT 2018 | ACMG Annual Clinical Genetics Meeting



Dr. Manisha Balwani

For the first time, the APF exhibited at the American College of Medical Genetics and Genomics (ACMG) annual conference, which offers a high caliber scientific program

that presents the latest developments and research in clinical genetics. All year they provide education, resources and a voice for more than 1,600 biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals committed to the practice of medical genetics. This was an opportunity to raise awareness about the porphyrias among clinicians who treat patients with metabolic conditions. Our own Dr. Manisha Balwani, Porphyria Expert, Icahn School of Medicine at Mount Sinai, New York (seen in photo talking to an attendee) presented a paper at the conference – she also spent time in the exhibit booth answering questions!

## RARE DISEASE WEEK ON CAPITAL HILL 2018 and RARE DISEASE DAY AT NIH



Edrin Williams (APF, Director of Patient Services) and Kristen Wheeden (APF, Director of Development) represented the American Porphyria Foundation this year at the 2018 Rare Disease Week on Capitol Hill events and at Rare Disease Day at NIH. These events included attending the Legislative Conference and Lobby Day where Edrin visited key Congressmen's offices to educate them about porphyria and request greater funding for research. The Legislative Conference included discussions on the Open Act,

Advancing Access to Precision Medicine Act, Drug Regulation and the Orphan Drug Act, Advocacy for Young Adults and the Rare Disease Congressional Caucus to name a few. With 7,000 rare diseases affecting 350 million people worldwide, our APF staff made sure that YOUR voices were heard. The APF also participated in Rare Disease Day at the National Institutes of Health (NIH). This week provided the opportunity for us to be among patients, advocates, health care partners, industry leaders, and many more who know what RARE means to this community. What can you do to help? Contact your State Representatives and Congressmen and ask that they join the Rare Disease Congressional Caucus! This helps bring public and Congressional awareness to the unique needs of the rare disease community and creates opportunities to address roadblocks in the development of and access to crucial treatments. The Caucus gives a permanent voice to the rare disease community on Capitol Hill. Call the APF Office to learn more!

## TELL US YOUR STORY!



The APF website includes comprehensive content on all areas of porphyria. It is also home to the personal side of porphyria. Nearly 150 APF members have shared their personal porphyria story to post on the website. Have you shared your profile with us? If not, take this opportunity to submit one. If you've already shared your story with us, now is a good time to make updates or refresh it. Don't forget to include a clean, sharp picture to accompany your profile. Thank you for taking the time to put a face on Porphyria and introduce others to the challenges we face. This is a wonderful way for newcomers or those interested in learning more to truly understand the diagnostic process, the burden of the disease, and the impact on quality of life by connecting this complicated disease to a real person. It is also a valuable area to help sufferers realize that they are not alone! If you are interested in submitting your porphyria story, please contact the APF office on 1-866-APF-3635. Tips for Writing a Compelling Profile Story:



- 📌 Open with a strong soundbite that hooks the reader and cover the most important parts (who, what, where, when, why)
- 📌 Use words wisely. Profiles should be between 300-500 words.
- 📌 Short sentences are powerful. Variety in word choice and sentence length keeps writing interesting.
- 📌 Let them hear your voice. Connect with readers writing in a conversational tone. Tell your story as if you were talking to your best friend. Share the most critical points and summarize the rest.
- 📌 Show – not just tell. Descriptive words engage the reader and give more clear understanding to support what you're saying.

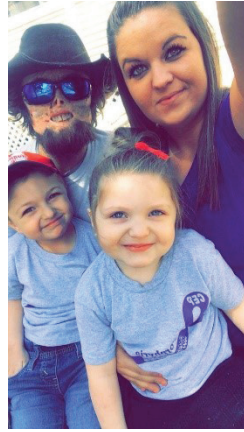


# THE WORST KIND OF PAIN IS WATCHING SOMEONE YOU LOVE IN PAIN



by Holly Hamilton for Justin Hamilton (CEP)

I am married to Justin Hamilton, who has Porphyria (CEP). I still remember the first day I met him like it was yesterday. I remember thinking he must have been in some kind of accident. Immediately I noticed his outgoing personality. It did not take long for Justin and I to become close and best friends. I started to see Justin's struggles with Porphyria and it broke my heart. Justin was always willing to help anyone he could, and God knew exactly what he was doing when he put Justin in my path that day. I have never looked at Justin and thought about his scars or disfigurements. I have always looked at him and seen a handsome, loving, sweet, caring, funny, and just great guy. We got married and now have two beautiful children. I started to look more into Justin's disease, tried to learn as much as I could about Porphyria and what I could do to help him. Watching the times he would have really bad blisters or be in pain just truly breaks my heart and still does to this day. I would do anything for him to be able to live a normal pain free life. Each day is a struggle. Justin has troubles with daily things such as unbuttoning his pants, opening jars or medicine cups, or opening doors (his fingers won't bend). I knew Justin's struggles the day I married him, and I chose to marry him because he is a wonderful man who loves me unconditionally. I do not mind taking the extra time and work to help him if that means it will be less painful or frustrating for him. There are days it's exhausting. A lot of the time I forget to take care of myself. But I know not to take my life for granted. I know that I have it easy



compared to the pain and struggles I have to see my husband endure each day. There is nothing worse than watching the person I love most lay on my lap and cry begging for that pain to just go away. Watching your husband watch his kids play outside while his son is begging his daddy to come play with him some more. But his daddy has already gotten too much sun so he can't go out and play. The look in my husband's eyes as his heart breaks that he cannot go and play with his kids more is heartbreaking. I do believe God chose Justin because he knew he was strong

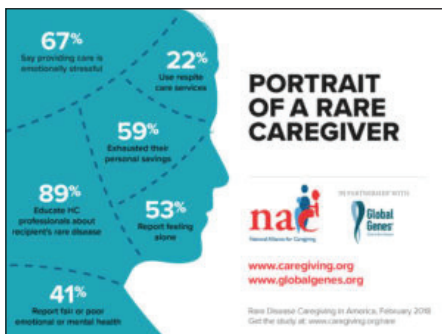
## If only I could take my husband's pain away just for one day.

enough to live this life with Porphyria. I do believe he knew how many lives Justin would change and what an inspiration he would be to others. Being a caregiver for the ones we love is challenging but I wouldn't have it any other way! Just remember you are not alone and the physical and emotional toll Porphyria is taking on your loved one is something you can never imagine. So be patient, understanding, and caring in every situation. There are going to be good days and there are going to be really bad days. But knowing they have someone in their corner will make all the difference in the world. If only I could take my husband's pain away just for a day. The worst kind of pain is watching someone you love in pain.

## CONGENITAL ERYTHROPOIETIC PORPHYRIA (CEP)

CEP is a very rare genetic disorder that affects only approximately 200 cases reported worldwide. The most common symptom is hypersensitivity of the skin to sunlight and some types of artificial light, with blistering of the skin occurring after exposure. It is an inherited metabolic disorder resulting from the deficient function of the enzyme uroporphyrinogen III cosynthase (UROS), the fourth enzyme in the heme biosynthetic pathway. Learn more at [www.porphyrifoundation.org](http://www.porphyrifoundation.org).

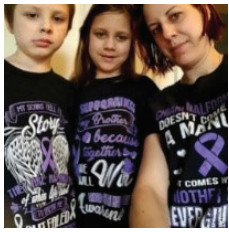
## PORTRAIT OF A RARE CAREGIVER



A study of over one thousand rare disease caregivers, *Rare Disease Caregiving in America*, was recently released. The goal of this study was to better understand the impact of rare disease on the caregiver. An estimated 25-30 million Americans live with a rare disease. This deep dive into the lives of rare caregivers suggests that it has a broad and lasting impact, in both daily life and long-term well-being. A defining feature of the rare caregiver is that of expertise. They become extremely knowledgeable about the condition and work to educate others on how best to take care of their loved one. These percentages highlight the impact of caregiving: 89% educate Healthcare Professionals about recipient's rare disease, 67% say providing care is emotionally stressful, 71% provide care to someone with genetic disease, 38% feel their local hospital cannot handle the underlying disease or condition, and 34% have difficulty accessing treatments or therapies for symptom management. The study resulted in policy recommendations, including

increased supports and services, given the enormity of the role they play. The APF recognizes the toll caregiving takes on the loved one of someone with any type of porphyria. We THANK YOU for being there for your child, spouse, family member, friend. We hope you take care of your own health as well! As always, please reach out to the APF for any support you may need. (Reference: *Rare Disease Caregiving in America*, National Alliance for Caregiving, February 2018).

## MEET APF MEMBER KIMBERLY MCINTYRE



Diagnosed with EPP just seven years ago at the age of 27, Kimberly also has a sister who also lives with the disease. It took a physician to know what to test for to finally find a diagnosis. A reaction feels like she is “burning from the inside out.” It takes a full week to recover using only a cool fan to relieve the horrible PAIN! Kim avoids a reaction by wearing long sleeve shirts and covering up – but heat can be a trigger for her as well. She typically stays in the shade on any day because it is too risky to tempt a reaction. A favorite indoor activity is watching movies with her kids. It’s difficult when

her son wants her and his sister to play outside on a sunny day and they are not able to do it. Growing up, it was difficult to share her condition with others due to a feeling of embarrassment – but now she doesn’t care. She shares that she is “allergic to the sun and it hurts more than you can imagine.” There was one-point she had a severe reaction and just wanted to give up. “I didn’t want to live this life, but now that I am an adult I realize I am stronger than this and I need to be for my kids.” Kimberly’s daughter now also lives with EPP. She wants to ensure that she is comfortable with sharing with others about her condition. She encourages her daughter and others with EPP to talk to people with the EPP because they understand and are there for you when you need it.

## IN MEMORY & IN HONOR

### DR. RICHARD JAMES HOWE



The APF has lost one of our most ardent supporters, beloved husband of Desiree Lyon Howe. Dr. Richard James Howe died peacefully at his home in Santa Rosa Beach, Florida on March 20, 2018 at the age of 89. Dr. Howe graduated with honors from Breck School, St. Paul, Minnesota and entered the University of Minnesota where he earned his B.S., M.S. and Ph.D. with distinction in Mechanical

Engineering in 1953. In 1965, he was selected as a Sloan Fellow at Massachusetts Institute of Technology. In 1978, he joined Pennzoil Company as Vice President of Corporate Communications and became President and Chief Operating Officer in May 1985. Following his retirement, Dr. Howe was treated successfully for prostate cancer and subsequently became one of the nation’s leading lay authorities on the disease. His illustrious business career gave weight to his voice in building the early prostate

cancer community of survivors and increased research funding. Dr. Howe was also an avid collector. His most passionate interest was in mechanical musical instruments and associated literature. Dr. Howe was active in Seaside Florida Chapel, Second Baptist Church and also serving on the boards of the Houston Grand Opera, Houston Ballet, United Way, Florence Crittendon Home, the American Porphyria Foundation and The Kelsey-Seybold Foundation. Dick and Desiree were married 21 years. During that time, both were determined to make their lives count for others in service to God and engaged in numerous PORPHYRIA and cancer advocacy efforts, including a speaking tour on prostate cancer in over 100 major hospitals across the country and providing their home to patients in need. Dick helped Desiree with APF projects lending his astute business acumen and organizational skills. The twosome also provided their home to porphyria patients who were seeking nearby experts. Dick lovingly would assist needy porphyria patients with their utilities, insurance payments, hospital bills, and a host of compassionate deeds. Friends and family speak of his character as a moral compass; his humor as the “king of one liners;” his happiness as contagious; and his friendship and love as all encompassing. He will be missed by all.

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

#### IN MEMORY:

Consortium Physicians, Drs. Karl E. Anderson, Robert J. Desnick, D. Montgomery Bissell, Herbert L. Bonkovsky, John D. Phillips, Manisha Balwani, Ashwani K. Singal, Makiko Yasuda, Larry U. Liu, Brenden Chen for **Richard (Dick) J. Howe, Ph.D.**; Sharon P. Dill, Dr. Herbert and Marilyn Bonkovsky, Monica Fleegel for **Richard (Dick) J. Howe, Ph.D.**; Sharon I. Koch for **Shirley and Ben Krovetz**; Daniel D. Diddlemeyer for **Florence Diddlemeyer**; Donald and Linda Johnson for **Peggy Lewis Johnson**; Michael P. Farina for **Vincent K. Farina**; Davida Hansen for **Kathi Carr**; Marie Sidoti for **Frank Nicchio**; Marcella Palmeri for **Breanne Alvarez Vazquez**; William and Marylou Rickert for **Gina Marie R. Opperman**.

We also thank those who honored a friend or family with a generous donation to the APF.

#### IN HONOR:

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