



AMERICAN PORPHYRIA FOUNDATION

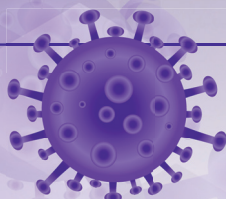
1st Quarter, 2021

# 2021

The APF extends our gratitude to each of you for your tremendous support during this past historic year. You are

the heroes that embraced the mission of the APF and championed the programs and services that benefit all members of the porphyria community, which included a continued relentless focus on research. The APF worked hard to pivot and expand our programs to meet the needs of the community amid the global pan-

dem. This work has staged the porphyria community for a busy and productive 2021. Read on to learn about research studies, clinical trials, patient education meetings, updated physician education materials, advocacy opportunities, awareness week activities, stories about members in our community and so much more. The entire APF team is here for YOU and we are all supported by our dedicated porphyria expert physicians. We have much hope for the future, and our community efforts should mirror the words of Dr. Chris Austin, Director of NIH National Center for Advancing Translational Sciences, "Hope is ineffective without action!" APF looks forward to serving you all in 2021 and beyond!



## COVID-19 and PORPHYRIA

*Updates and statements from porphyria experts will be listed on [www.porphyrifoundation.org](http://www.porphyrifoundation.org).*

### 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.

### MRNA COVID-19 VACCINES – SIMPLIFIED

Many of our members have asked about the mRNA COVID-19 vaccine and why it is different from the other vaccines. Here is a simplified explanation. The mRNA vaccine is a new type of vaccine, but scientists have been researching it for decades. These vaccines can be developed in a laboratory using easily available materials, which is why they can be developed faster than other vaccines and why they can also be standardized easier and faster. Unlike the vaccines that trigger an immune response by putting a weakened or inactivated virus into our bodies, the mRNA vaccines use a different process. The mRNA instructs our cells how to make a harmless piece of a protein that triggers an immune response inside our bodies. Note the mRNA never enters the nucleus of the cell. This is important because the nucleus contains our DNA. Next, the body gets rid of the protein piece after it breaks down the instructions from mRNA. The cell displays the protein on its surface. The immune system recognizes that the protein does not belong there and begins an immune response and making antibodies. Thus, in most cases, the people who are vaccinated are protected without being sick with COVID-19. Of great importance is that the mRNA vaccine process may be the wave of the future as it gives us protection without exposing us to the live or non-live virus. Both the Moderna and Pfizer/BioNTech vaccines require a primary dose shot and a booster shot. With Pfizer, the booster is 21 days later and Moderna is 28 days later. Pfizer's shot contains 30 micrograms of vaccine and Moderna 100 micrograms. The shots have similar side effects.

### COVID-19 AND PORPHYRIA

The APF, alongside the Porphyria Experts, is committed to keeping our member community abreast of the latest COVID-19 developments related to porphyria. The Porphyrias Consortium has developed an official statement regarding the COVID-Vaccination, also available on [www.porphyrifoundation.org](http://www.porphyrifoundation.org).



## UPCOMING EVENTS

### RARE DISEASE DAY 2021



Rare Disease Day is an observance typically held on the last day of February to raise awareness for rare diseases and improve access to treatment and medical representation for individuals with rare diseases and their families. Rare Disease Day 2021 was marked

by awareness efforts around the world, and events at NIH and the FDA in the United States. 1 in 10 individuals live with a rare disease making this an important day to highlight the needs of millions Americans living with a rare disease. NIH organized a day-long event including presentations from experts and patients to nearly 1000 attendees. Kristen Wheeden, APF Executive Director, moderated a discussion regarding changes in research and clinical studies related to Covid-19. On March 5, the FDA hosted a virtual meeting that highlighted strategies to support rare disease product development.



**SHOW YOUR STRIPES** is the theme of Rare Disease day, alluding to the zebra as a symbol for rare disease, which started around 1940. This comes from a quote by Dr. Theodore Woodward, “When you hear hoofbeats, think horses, not zebras.” and “When you hear hoofbeats behind you, don’t expect to see a zebra.” Most physicians are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. Through rare disease awareness and showing our stripes, an increasing number of physicians include rare disease as a potential diagnosis. We encourage healthcare professionals to THINK PORPHYRIA when patients present with symptoms consistent with a type of porphyria.



## PORPHYRIA Awareness Week

APRIL 10-17, 2021  
#LETSTALKPORPHYRIA



*Porphyria Awareness Week is an opportunity for you to create awareness within your community! Let’s talk about it! We strive to dedicate this week to promote Porphyria awareness, reduce the stigma associated with porphyria through education and increase support for those impacted. Greater awareness can equal earlier diagnosis, better management, and access to life-altering treatments.*

### #LETSTALKPORPHYRIA

focuses on starting the conversation about Porphyria. This campaign encourages our community members to educate and partake in a dialogue with their peers and healthcare providers about Porphyria.

How will you get the discussion started? Get creative and let us know how you will get involved. We hope Porphyria Awareness Week 2021 empowers you to raise porphyria awareness within your communities.

The American Porphyria Foundation is here to support you with ideas, brochures, materials, social media files (including Logo Files, Porphyria Fact Sheets, Press Release – and any other support that you may need to raise Porphyria awareness about Porphyria in your community.

Visit [www.porphyrifoundation.org](http://www.porphyrifoundation.org) for daily updates and resources on Porphyria Awareness Week 2021.

### WHAT CAN YOU DO?

**Wear purple for Porphyria!** Some have had a class or an office wear purple for the day in support of porphyria.

**Educate friends and family.** Send an email, a social media post, or send a letter about your experience with porphyria. This is a great time to virtually talk to a class or host a virtual lunch and learn.

**Tell your story to local media.** Help others by spreading your experience. Television, newspapers, community magazines are looking for people who have undertaken the challenge with a rare.

**Help others by sharing knowledge** about porphyria with your community, including your family members, friends, and the physicians in your local hospitals. Suggest that they host a virtual seminar or a local meeting where you can hand out materials.

**Share your story on social media.** It is an easy and effective way of getting porphyria in the public eye.

The American Porphyria Foundation will continue to partner with other international porphyria advocacy organizations to increase awareness around porphyria.

**SHOP NOW**

Visit our website for new merch!

**BUFFS, WRISTBANDS AND SHIRTS, OH MY!**

[WWW.PORPHYRIAFoundation.org](http://WWW.PORPHYRIAFoundation.org)



## GLOBAL PORPHYRIA ADVOCACY COALITION (GPAC) VIDEO

GPAC is an umbrella organization that provides a unified, collaborative voice for porphyria patients worldwide. It connects, supports, and engages national porphyria patient advocacy organizations, through the provision of an integrated international network, in an effort to gain awareness, access to diagnosis, management and treatment of the porphyrias. Porphyria advocacy group leaders from around the world are now recording a video to lift their voices and raise awareness about porphyria. Leaders in a dozen countries will share how they are impact awareness among patients, physicians and the public. Special thanks to Alnylam Pharmaceuticals for sponsoring and organizing this project!

## 2021 PATIENT EDUCATION MEETINGS

In keeping with COVID safety protocols, our patient education meetings and educational series will continue to be on Zoom for the foreseeable future.



**January 28, 2021** - Hetan-shi Naik, PhD, Professor and Clinical Genetics Counselor at the Icahn School of

Medicine at Mount Sinai, led a presentation on genetics and porphyria. Patients were treated to a discussion on “genetics 101” overview followed by an exploration of genetics in the porphyrias.

**February 25, 2021** - Ms. Karli Hedstrom, Senior Research Coordinator at the Icahn School of Medicine at Mount Sinai, led an education session on the importance of research participation. Putting “Research is the Key to Your Cure” into action was the focus on Ms. Hedstrom’s talk. Why participate in research? What can we learn? – were the main topics discussed.

We will continue to schedule informative and supportive meetings. Have an idea for a meeting? Give us a call and let us know.

Email Director of Patient Services, Edrin Williams, at [edrinw@porphyriafoundation.org](mailto:edrinw@porphyriafoundation.org) to be reminded of upcoming events.



**NORD**  
National Organization  
for Rare Disorders

## NORD RAREINSIGHTS® REPORT

The National Organization for Rare Disorders (NORD) published a new RareInsights® report today looking at comparative trends in rare disease care and treatment in the U.S. over a 30-year period.

### Key findings include:

- » 88% of people today reported that they would consider using an investigational drug or treatment, compared to 62% in 1989.
- » 16% of individuals today reported that they had already participated in a clinical trial for their rare disease, compared to 12% in 1989.
- » 17% of individuals today have already relocated or are considering relocating to access care for their rare disease, versus 8% in 1989.
- » 2% of respondents today reported that they did not have health care insurance, versus 9% in 1989.

The full report is on the NORD website at [rarediseases.org/advocate/rareinsights](http://rarediseases.org/advocate/rareinsights).



The American Porphyria Foundation is proud of our Platinum membership in the National Organization of Rare Disorders.

## PATIENT REPORTED OUTCOMES (PROS) AND PORPHYRIA

A patient-reported outcome (PRO) is a health outcome directly reported by the person who experienced it related to a specific treatment or condition. A PRO is distinct from other health outcome measures that may be reported by someone else, including a physician or investigator. PROs are critical in research and have increased through electronic means in recent years. PROs can be used for general care improvements, research, and clinical trials. There is a range of potential PRO measurements – many that you see in studies in porphyria. When you receive a request to participate in a survey, questionnaire, interview, or clinical trial related to porphyria, know that the research community is seeking to understand the impact of living with porphyria from YOUR point of view. #ResearchIsTheKeyToYourCure

### PROS IN PORPHYRIA

#### PROs through Electronic Diary

The Mitsubishi Tanabe MT-7117 Phase 2 clinical trial, completed in 2019, titled Study to Evaluate Efficacy, Safety, and Tolerability of MT-7117 in Subjects With Erythropoietic Protoporphyrin collected critical PROs as a part of the array of collected data to analyze the treatment. The primary outcome measure in this study was the ‘Change from baseline in average daily duration of sunlight exposure without symptoms’ ([clinicaltrials.gov](http://clinicaltrials.gov)). To collect accurate data, patients reported their daily exposure in an electronic diary. This pivotal study, using patient reported outcomes paved the way for a Phase 3 clinical trial.

#### PROs through 1:1 Interviews

An important study titled Patient Perspective on Acute Intermittent Porphyria with Frequent Attacks: A Disease with Intermittent and Chronic Manifestations (The Patient, 2018) focused on the impact of the patient experience on daily living. Data was collected through one-on-one interviews. The study highlighted the chronic manifestations of living with AIP in addition to the intermittent acute attacks.



### SHADOW JUMPERS

## FIND YOUR SHADOW 2021!

Applications are open for our fourth annual **FIND YOUR SHADOW** program. Last year, we selected Anthony Zamora and Cheyenne Ludwig as our recipients. Unfortunately, due to COVID restrictions, we had to roll over their awesome experiences into 2021. That is not stopping Shadow Jumpers from looking for new submissions to help take on the sun in 2021. Two years of experiences loaded into what we hope is an eventful end of the year.

We are looking for kids under the age of 18 attempting to do something they have always wanted to try but may have been holding off from doing because of their EPP. Whether attempting recess, an outdoor sport/camp, a specific family vacation or more, nothing is off limits. We ask EPP families to submit their story and tell us how we can help make living with EPP easier. Go to SHADOW JUMPERS on the APF website for more details. *Applications are open now until Friday, April 30th, 2021, and recipients will be announced in May!*

## INTERNATIONAL CONGRESS ON PORPHYRINS AND PORPHYRIAS 2021/2022

Due to the global pandemic, The European Porphyria Network (Epnet) and the organizers in Sofia (Bulgaria) have decided to postpone the 2021 International Congress on Porphyrins and Porphyrias (ICPP). **The new dates for the ICPP 2022 will be: September 4-7th 2022 in Sofia, Bulgaria.**



## RESEARCH

### MITSUBISHI PHASE 3 CLINICAL TRIAL FOR EPP/XLP More Study Sites Available!



Mitsubishi Tanabe Pharma

**ATTENTION EPP/XLP MEMBERS!** Limited slots remain for this Phase 3 trial. This study includes ages 12-75. Call the APF to be referred to a Research Coordinator at a study site – or to confirm your study site location. New study site locations have recently been added. If you are interested in learning more or confirming, please contact Edrin Williams, Director of Patient Services. Phone: 301-312-8741 E-mail: [edrinw@porphyriafoundation.org](mailto:edrinw@porphyriafoundation.org).

### POWER STUDY IN ACUTE PORPHYRIA

Acute Porphyria Patients needed! Kantar, an independent research agency, is collaborating with sponsoring company Alnylam Pharmaceuticals, and with the assistance of the patient advocacy groups the American Porphyria Foundation, the Global Porphyria Advocacy Coalition, and the International Porphyria Patient Network to conduct research on Acute Hepatic Porphyria (AHP) also known as Acute Porphyria (AIP, HCP, VP, ADP).

In this context, we along with the American Porphyria Foundation invite you to participate in the Porphyria Worldwide Patient Experience Research (POWER) study. Your input is critical to increasing awareness and understanding of AHP and the needs of patients living with this condition. Purpose of this research: The main objective of the research is to raise awareness on the impact of AHP on patients' lives and better understand how disease manifestations or changes over time impact patients' lives. For More Information on the Study go to: <https://survey.euro.confirmit.com/wix/6/p151984637976.aspx?ctn=1&l=2057>



Don't let EPP-amnesia hit you this Spring! Prepare early for the process to begin treatment with Scenesse®. Start by accessing [www.scenesse.com](http://www.scenesse.com) and completing the Savings Program information to be assigned a unique identification number. You will then be contacted with location information nearest you to begin the insurance authorization process. This can take several months to complete – so make sure to get a headstart!

### CAM & CANNABIS SURVEY in AIP and EPP

#### AIP

If you are 18 years or older, you are invited to participate in an anonymous survey assessing Complementary and Alternative Medicines (CAM) and Cannabis use in AIP to help determine whether these may improve AIP symptoms. CAM is the term used for medical products and practices that are not part of standard medical care. For example, acupuncture, aromatherapy, biofeedback, and many more. If you have never used CAMs or cannabis this is still very useful information for the researchers. Participation will take approximately 20 minutes.

If you are interested in learning more or participating, please visit: <https://j.mp/2MHNVD>. If you have completed this survey in the past please do not complete it again.

#### EPP

If you are 18 years or older, you are invited to participate in an anonymous survey assessing Complementary and Alternative Medicines (CAM) and Cannabis use in EPP to help determine whether these may improve EPP symptoms. CAM is the term used for medical products and practices that are not part of standard medical care. For example, acupuncture, aromatherapy, biofeedback, and more. If you have never used CAMs or cannabis this is still very useful information for the researchers. Participation will take approximately 20 minutes.

If you are interested in learning more or participating, please visit: <https://j.mp/3dVeNGZ>. If you have completed this survey in the past please do not complete it again.



### CURRENT RESEARCH INITIATIVES

are listed on the APF website: [porphyriafoundation.org](http://porphyriafoundation.org)



## ACG PRESIDENTIAL POSTER AWARD

Congratulations to Dr. Herbert Bonkovsky (Porphyria Expert, Wake Forest University,

NC Baptist Medical Center, Winston-Salem, NC) and his outstanding team for winning the Presidential Poster Award in the Liver category at The American College of Gastroenterology (ACG) Virtual Annual Scientific Meeting. View poster, titled *Clinical Outcomes in Patients With Acute Hepatic Porphyria Treated With Givosiran Who Stopped Hemin Prophylaxis at Study Entry: A Post Hoc Analysis of Data From the Phase 3 ENVISION Study Through Month 12*, here: <https://www.eventscribe.net/2020/ACGPosters/PosterSpeakers.asp?goToLetter=B&pfp=PosterPresenter>.

## DR. SAMUEL SILVER LIFETIME ACHIEVEMENT AWARD



Our congratulations go out to Dr. Samuel Silver (Porphyria Expert, University of Michigan, Hematology Clinic), who recently received 2021 The Lifetime

Achievement Award from the Michigan Society of Hematology/Oncology.

Dr. Silver established Michigan's first statewide consortium on quality breast cancer care, in addition to this latest honor, he has received a Statesman Award from the American Society of Clinical Oncology for his significant volunteer efforts; as well as the American Medical Association's (AMA) Gordon Award for his work on its Current Procedural Terminology (CPT) Editorial Board, which identifies codes for medical procedures.



## HEME SYMPOSIUM 2021!

Stay tuned for important update regarding the Heme Symposium scientific workshop and patient meeting. An updated conference date and agenda will be available soon.

## GLOBAL NEWS

As the number of Global people with porphyria rises in our APF database, so does the number of people in countries outside of the United States who are using our website and social media platforms. Imagine we now have people from over 100 countries viewing our website and thousands on our social media groups.

One of those users reached out to the APF when a family member from Florida visited relatives in Ecuador and suffered a serious AIP attack. When the patient became critical, she was admitted into the ICU in Ecuador. Since the hospital did not have the appropriate treatments and could not have her transferred to the US, the family sought assistance from the APF, namely the Global Director. Immediately we contacted Dr. Cynthia Levy, an esteemed porphyria expert in Miami, and the Air Evac and transfer teams. The patient was evacuated to the Florida hospital. We sincerely thank Dr. Levy, who kindly provided the porphyria expertise during the crisis. The patient is now greatly improved.

These stories are not infrequent. Patients and doctors around the world continue to reach out to the APF to seek help from experts. For example, within a few weeks, experts Drs. M. Kazamel, K. Anderson and H. Bonkovsky consulted with doctors in Saudi Arabia, Jordan, Pakistan, Egypt, and Oman to assist patients suffering from acute porphyria. We sincerely thank our experts for providing such life-saving expertise to doctors around the globe.

Another major effort to educate patients are our Zoom meetings. International patients are the focus of our language-based calls. We recently hosted a Spanish-language call led by Kika Shabot, director of the Mexico Porphyria Society, and facilitated another Zoom meeting for patients in Colombia hosted by the Porphyria Foundation of Colombia.

At present, our Global Program is:

- » locating patients for Mitsubishi EPP research projects in specific international sites,
- » assisting a study on patient experience in specific countries outside of the US.
- » seeking leaders for support groups in South Africa, India,
- » formulating support groups in countries like Pakistan, Argentina and Egypt
- » assisting in reimbursement project in Canada,
- » helping patients and physicians in 76 countries.
- » providing education worldwide.
- » initiating Zoom calls.

If you are an international patient, physician, family member or caretaker, and would like educational materials, please contact me at [lyonapf@aol.com](mailto:lyonapf@aol.com) or the APF!



Leda Bussman, Director of the Associação Brasileira de Porfiria (ABPRO), has greatly impacted porphyria education and awareness in Brazil. She has initiated conferences and training for physicians and patients, established a registry of patients and doctors, facilitated US expert educational sessions, managed a DNA testing project, and helped porphyria patients attain diagnosis and treatment. This is a family affair with her son, Janary, and daughter, Bene.



Thanks to an international donor, we were able to maintain the Global Program.



## HEPATACELLULAR CARCINOMA AND ACUTE PORPHYRIA

Several retrospective and recent studies by porphyria researchers and clinical experts in the United States and Europe have indicated an association between hepatocellular carcinoma and acute hepatic porphyrias (AIP, HCP, VP and ADP). In fact, they have purported that this high risk of hepatocellular carcinoma in acute porphyrias warrants that these patients should be evaluated periodically for hepatocellular carcinoma by ultrasound surveillance.

The reason researchers feel this occurs is that genes encoding for heme biosynthetic pathway may not act as tumor suppressor genes and chronic increased levels of  $\delta$  aminolevulinic acid could lead to the generation of free radicals and subsequently to hepatic carcinogenesis. Therefore, it is recommended that acute patients **SPEAK WITH YOUR DOCTORS ABOUT ORDERING AN ULTRASOUND TO CHECK FOR HEPATACELLULAR CARCINOMA.**

As well as hepatocellular carcinoma, patients with acute porphyrias also can experience an increased risk for developing kidney and liver problems and high blood pressure. These conditions can impact their generally normal life span.



## COVID UNCOVERS A CASE OF ACUTE PORPHYRIA

SAN ANTONIO, TX – KTXS12ABC recently reported on a porphyria case related to COVID-19. In the report by Alejandra Guzman-Tracy, a young woman became paralyzed after a battle with COVID-19 due to a rare genetic disorder – Acute Intermittent Porphyria. The 27-year-old, Marisela Torres, tested positive for COVID after developing every symptom except shortness of breath. Doctors found the cause after a few weeks. According to Torres, “COVID triggered, what I have, which is something called porphyria. It’s a genetic thing I was actually born with.” Marisela was on a ventilator for about five months, including her birthday in November, and lost 58 pounds in the process. The doctor maintained that “she and her mom were very, very passionate about like keep fighting, keep fighting.” Mari’s healthcare team says her recovery is a miracle. They were able to wean her off the ventilator and after six months she can breathe on her own. With rehabilitation, Marisela has been able to get back on her feet.

## THANK YOU TO 2020 DONORS

As we launch into 2021, we want to take a moment to thank all our donors who supported our mission in 2020. Your generosity helped the APF make great strides in research and patient advocacy. We would also like to thank the generous employers of our donors who matched their employees’ donations. Many employers make dollar for dollar matches. If you would like to help the APF cause and make your donation go even further, please consider checking with your employer to see if they have a matching program.



## ASH Clinical News™

**A Primer on Porphyrias** was published in the American Society of Hematology (ASH) printed and digital journals in early February. Focused on the experience of the Porphyria Satellite Center at the University of Washington, the article delved into diagnosis, pathogenesis, clinical features, and novel therapeutics. Though the porphyrias are treated by a variety of medical specialists, hematologists are often the most common treating physicians of the porphyrias given that deficiencies lie in the heme biosynthetic pathway. Of note, the APF website experienced an uptick in visits from healthcare professionals after the release of the article – the more physicians who are educated in the porphyrias, the better for the patient community!

## NIH COALITION OF PATIENT ADVOCACY GROUPS (CPAG)– WEBINAR SERIES

**“Working with Industry in the Conduct of Clinical Trials,”** was the title of a recent webinar held virtually on **Thursday, February 25, 2021**, that focused on the relationship between industry partners and patient advocacy groups. A productive discussion took place on what types of assistance industry may ask of patient groups including developing protocols; helping to recruit patients; helping to recruit clinic sites; and using the resources of the patient groups for outreach. This session also focused on questions to ask industry when entering a partnership. Presenters include patient advocacy group leaders and industry partners – including Kristen Wheeden, APF alongside Jordanna Mora of Alnylam Pharmaceuticals. This is the third in a five-part series on clinical trials.

## NEW MEMBER STORIES!

We want to invite you to share your story with the porphyria community. The APF office receives regular feedback that the stories listed on our website have helped members feel less isolated and facilitated with diagnosis and treatment options. Stories submitted should be about 500 – 2000 words and full of your personality. Make sure to include information about your specific porphyria type, your diagnostic journey and how this disease has impacted your life. Please also attach a recent photo. With permission, all stories will be featured on the APF website. We will also feature select stories in our quarterly newsletter. Send your stories to Edrin at [edrinw@porphyriafoundation.org](mailto:edrinw@porphyriafoundation.org) along with a recent photo. You will also be requested to complete a waiver. We look forward to receiving your stories!



## CONTRIBUTE TO UPCOMING APF NEWSLETTERS

Calling all writers! If you have a story, an inspiration, a memory, or experience to share, the APF welcomes your contribution to our quarterly newsletters. Patients learn so much from one another – and we welcome your thoughts and writing talent! Email [kristen@porphyriafoundation.org](mailto:kristen@porphyriafoundation.org) to initiate.



## REMEMBERING MICHELLE MARIE SIUTA

APF fondly remembers our friend and AIP patient Michelle Siuta, who passed away last April, while undergoing a double organ transplant for a kidney and liver. Michelle Marie Siuta was strong, creative, smart, thoughtful, honest, and fun loving. Her energy could light up any room. She was a beautiful soul, inside and out. After growing up on a farm, Michelle pursued a career in engineering. Due to Michelle's health concerns, she was forced to cut her engineering career short. Her goal had been to gain personal experience in crop production, a deeper understanding of farm management, and the entrepre-

neurial skills to positively contribute to her family's existing farm. She was incredibly passionate about art, music, sports, and dancing. She enjoyed learning about different cultures and had the ability to brighten the mood and make people laugh. She had hoped to travel extensively and explore the world - when her health allowed. Michelle gave back to the community by being an advocate for the American Porphyria Foundation and serving on a board to educate pharmaceutical companies about the impact of porphyria. She was a volunteer Fire-fighter and graduated from her local Sheriff's Civilian Police Academy. Michelle's faith in God was unwavering, it helped her to persevere, despite the health struggles she faced, struggles she refused to be defined by. Authentically herself, Michelle's own

words sum up her short, yet beautiful life: "Dreams are nothing if not fulfilled, they're only visions that appear. All your hopes and all your might could be washed away just like a tear. Nothing more, nothing less, it's so easy to lose your way. But if you're strong and don't give up, you will live your dreams someday." We send our deepest sympathy to the Siuta Family.

<https://zajacfuneralhomeinc.com/tribute/details/873/Michelle-Siuta/obituary.html>

*After her passing, Michelle's family honored her memory and mission to bring more awareness of Porphyria to patients and doctors through a tremendous fundraising effort. The APF will steward the funds with love and care, focusing on all who battle porphyria.*



## PORPHYRIA PIONEER DR. PETER TISHLER PASSES AWAY

It is with great sadness that we share the passing of Dr. Peter Tischler on January 18. He is survived by his wife of 60 years, in addition to his children, grandchildren and brother. A Harvard and Yale graduate, Dr. Tishler was an educator, researcher and clinical physician specializing in human genetics and orphan diseases. A preeminent expert in the porphyrias, Dr. Tishler was a member of the APF Scientific Advisory Board and oversaw the creation of the APF Safe/Un-safe Drug Database. The APF has heard from patients and physicians alike that Dr. Tishler was a champion in the porphyrias. We send our deepest sympathy and condolences to the Tishler Family.

## ARCHIVED APF NEWSLETTERS

We have heard from many APF members that have enjoyed the APF quarterly newsletter over the years. In fact, the first newsletter was published in 1984. "Remember...Research is the Key to Your Cure" has been included in every single newsletter since the first! An archive of all printed publications is kept in the APF office, but you can access the materials on [www.porphyrifoundation.org](http://www.porphyrifoundation.org) under "News" in the menu, which includes issues since 2005. Take a few moments to read about the research, physician efforts, conferences, meetings, and so much over the years. It is also a powerful reminder of how far we have come in research and treatment in the porphyrias!

## IN MEMORY & IN HONOR

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

### IN MEMORY:

Mary Crown for **Mary Hargett**; Jeffrey Halterman for **Karen Biscone-Halterman**; Michael & Carol Farina for **Vincent K. Farina**; Marvin & Susan Katz, Sandi Katz, Phyllis & Joel Kingsley, Marvin C. Rich, PhD, & Lawrence E. Leguire, PhD, Cynthia & Mark Levy, Jonathan Petuchowski, Leslie Yenkin for **Dr. Peter Tishler**; Anonymous, CNA Insurance, Melville Branch, Robert Festa, Danielle Gay, Julianna Elardo, Kaylee Groia, Tina & Ray Jensen, The Kleinfelder Family, Eric & Liza Licht, The McInerney Family, Glen Nile, Raymond & Terri Polk, Tracy & Chris Smith, The Timper Family, Chris Tine, The Tosun Family for **Kelli Paquet Quenzer**; Florence Kirshoff for **Ruth Taffet**; Diane L. Levere for **Richard D. Levere**; Paul & Barbara Mellon for **Clinton Lucas**; Kevin Paquet for **Diane Paquet**; Mary K. Pritchard for **Ralph Gray**; Christopher & Elizabeth Petersen for **Dr. Richard J. Howe**;

George Rusnak for **Carol Rusnak**; The Siuta Family for **Michelle Marie Siuta**; Thomas & Elaine Smuczynski for **Helen & for James Smuczynski**; Kathleen Toelkes for **Donna Pagano**.

### IN HONOR:

Marcia Alicea for **Tasha Alicea**; Biological Monitoring, Inc. for **Dave Gruber**; Beth Larsen & Phil Cecchini for **Hannah Moraski**; Gudrun Debes for **Julie Debes**; Karen DeWitt, Jean Lewis for **Kelly Roberts**; Steven Dossin for **Margaret Dossin**; Caroline Durning, The Sanford Family for **Meg Favulli**; Tiago Girao for **Isabella Girao**; Grayfred Gray, Lori Hanson, Paula Hendrix for **Ralph Gray**; Nicholas Guanciale for **"Pigskin Nick's" Annual Bowl Game Pick Em**; James & Deborah Halvis for **Edrin Williams**; Connie & Martin Helleson, Ernie Hyne for **Linda Hyne**; Florence Kirshoff for **Ruth Taffet**; Shirley Knodel for **Jennifer Streeter**; Diane L. Levere; for **Richard D. Levere**; Kathleen Toelkes for **Valine Jensen & Linda Peterson**; Ryan Turell for **Andy Turell**; WEGO Health for **Sean Albright**.

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