



AMERICAN PORPHYRIA FOUNDATION

4th Quarter, 2019

HAPPIEST OF HOLIDAYS AND WONDERFUL WISHES FOR A JOYOUS 2020!

This has been a year of advances! With two new FDA approved treatments, a successful Phase 2 clinical trial complete, and a NIH grant renewal of the excellent physicians of the Porphyrias Consortium, we have much to celebrate as we joyfully move into the coming year. The APF will continue to work to make 2020 a year of advances in research, education of physicians and patients, communication to our members, advocacy for all porphyrias, and global awareness efforts. Blessings to each of you – we are grateful for your support!



NIH AWARDS PORPHYRIAS CONSORTIUM 5-YEAR GRANT

We are delighted to announce that the National Institutes of Health (NIH) Rare Disease Clinical Research Network (RDCRN) has awarded a 5-YEAR GRANT RENEWAL to the Porphyrias Consortium. The **Porphyrias Consortium** includes six porphyria centers in the United States, as well as three current and four new Satellite sites, that provide expertise and experience in the diagnosis, management, and treatment of patients with porphyria. Together with the American Porphyria Foundation, the Porphyrias Consortium enables a large-scale collaborative effort to develop new strategies and methods for diagnosis, treatment, and prevention of illness and disability resulting from these rare disorders.



SCENESSE – FDA APPROVED!

On October 8, The Food and Drug Administration granted APPROVAL for Afamelanotide (Scenesse) for the treatment of Erythropoietic Protoporphyrria (EPP). At long last, US patients will have access to this life-altering treatment. **Congratulations** to you, our patient community, who fought for this approval for over a decade. We finally moved from gaining Orphan Drug status in 2008 to a FDA approval in 2019. Your hard work included participating in the Phase 2 and Phase 3 clinical trials, multiple letter campaigns, photo campaigns, an FDA Scientific Workshop, multiple small meetings at the FDA, advocating for Priority Review and so much more. Our hard work characterizing the true burden of this disease and the need for treatment finally worked. Contact the APF for updated information on the availability of Scenesse.

Patient Voice *My experience with Scenesse has been miraculous and life changing. I am able to fully tolerate all sunlight and artificial light without limits. I have become 'cutaneous normal!' – Jennifer Beck, EPP patient*

MITSUBISHI PHASE 2 TRIAL – SUCCESS!

Mitsubishi Tanabe Pharma Development America, Inc. announced successful completion of the Phase 2 clinical trial of MT-7117, an investigational oral treatment under development for the prevention of phototoxicity (including severe pain on exposure to sunlight) in patients with Erythropoietic Protoporphyrria (EPP). In this Phase 2 proof of concept trial, MT-7117 met its primary endpoint and was generally well tolerated with an acceptable safety profile. This study will pave the way for a pivotal Phase 3 trial.

GIVLAARI™ (GIVOSIRAN) – FDA APPROVED!



On November 20, the Food and Drug Administration granted APPROVAL for GIVLAARI™ (Givosiran) for the treatment of Acute Hepatic Porphyria. US patients will now have access to this novel preventative RNAi treatment. This approval is the first step in gaining access to GIVLAARI™ (Givosiran) in the US. Availability to patients will progress as Alnylam Pharmaceuticals pivots from FDA approval to commercial availability. Congratulations to YOU, our patient community, who participated in the pivotal Phase 2 and Phase 3 clinical trials that led to this approval. You are our medical heroes! Contact the APF for information on availability of GIVLAARI™.

Patient Voice *The approval of Givosiran™ is a leap forward for all patients with AHP. It has stopped my attacks and allowed me to live my life again. – Michael Boone, AIP patient*



REMEMBER...
Research is the Key to Your Cure!

PANHEMATIN® RESOURCE



The APF receives frequent requests for information on Panhematin® from both patients and physicians. The website available at www.panhematin.org is an excellent resource for patients and healthcare professionals for information related to access, support assistance, and proper dosing and administration. PANHEMATIN® is a hemin for injection prescription medication used to relieve repeated attacks of AIP. Panhematin® was approved by the FDA in 1983. Please contact the APF if you need further information related to this life-saving treatment for acute Porphyria.

ACCESS TO PANHEMATIN® IN CANADA

We have had many Canadian friends ask about how to get access to Panhematin® treatment. Here are the instructions:

1. The Patient should tell their hematologist or other physician (eg. Emergency or Internal Medicine) that Panhematin® is available at the hospital through the Canadian Blood Services (CBS) blood bank, NOT THE PHARMACY.
2. Panhematin® is 100% paid for by CBS, not by the hospital nor the patient.
3. Each hospital has personnel who manage the blood bank and who will know how to access Panhematin®.
4. Certain forms will have to be filled out by the treating physician such as the Patient Designated Plasma Protein Products Request form.

NATIONAL ORGANIZATION FOR RARE DISORDERS SUMMIT 2019

The Rare Disease Summit 2019 – with the theme of *The Time is Now* - brought together thought leaders from the FDA, NIH, ICER and other government and private organizations with leading roles in rare disease and orphan products. The APF was engaged in this annual meeting and left armed with the latest information on drug pricing, advancements in technology, orphan drug development and more topics applying to the porphyrias.



NEW SATELLITE PORPHYRIA CENTER LOCATIONS

We are pleased to welcome four new sites to our field of expertise. Stay tuned for bios from each new center! Simon Beaven, MD, PhD **University of California - Los Angeles**, Marshall Mazepa, MD & Greg Vercellotti, MD **University of Minnesota**, Amy Dickey, MD **Massachusetts General Hospital**, and Manish Thapar, MD **Thomas Jefferson University, Philadelphia, PA.**

WAKE FOREST- EDRIN AND DEE



The interaction between the APF and the research coordinators at our study sites is critical for patient referrals for clinical care, research studies and clinical trials. We depend on constant communication to ensure that our members are managed appropriately and efficiently. Edrin Williams, Director of

Patient Services, recently visited Dee Faust, Research Coordinator at Wake Forest Baptist Health University. The goal of his visit was to understand the perspective and needs of a coordinator in order to better do his job at the APF.

CHECK OUT THE NEW MERCHANDISE

on the APF Store
at porphyriafoundation.org



RARE DISEASE WEEK ON CAPITOL HILL

SAVE THE DATE FOR RARE DISEASE WEEK 2020!

Rare Disease Legislative Advocates and EveryLife Foundation for Rare Diseases will be hosting Rare Disease Week on Capitol Hill 2020 in Washington, DC. This week of events bring together hundreds of patients, caregivers, industry leaders and more to the nation's capital.

This event consists of a Legislative Day to learn about the legislative process, legislation currently under consideration by Congress, and effective advocacy techniques to build a relationship with members of Congress and staff. Patients and patient advocates will also visit offices of their members of Congress and their staff to advocate for legislation most important to their rare disease. Registration to this event is **FREE!** Registration for Rare Disease Week on Capitol Hill 2020 will open on January 3, 2020. We look forward to seeing you all there! Website: <https://rareadvocates.org/rdw>

MARK YOUR CALENDARS!

PORPHYRIA AWARENESS WEEK 2020

APRIL 18-25

How will YOU create awareness in your community?



THE BRIGHT SIDE OF EPP



Having EPP has been quite a journey. Symptoms started as a baby and at 59 years old, I am still sidelined from life in the light – like any-

one with EPP. The pain and isolation of living with EPP is a tough thing to endure both physically and mentally. But this article outlines a different side of EPP.

It was not until 2 years ago I was to embark on the upside of EPP – having noticed an online plea from a family in Denmark. The idea this family put forth was for their teenaged son, Joachim, with EPP, to be

exposed to different settings to help him gain additional confidence through a variety of experiences. My husband, Joe, and I opened our home to Joachim and he, in turn, stole our hearts. The hope was to show him how our family copes with EPP daily and for Joachim to practice his already fantastic English skills. We happily showed Joachim the fun things Boston and New England had to offer. In turn, he brought us joy in the form of playing a variety of games. He jumped right in to volunteer with us – both at the church and for Meals on Wheels. They treated him to Five Guys Burgers for helping, which pleased Joachim very much. The humor he brought to our home was priceless, making it hard to say goodbye at the end of his stay. But we remained in touch. This summer we

were absolutely delighted to learn that Joachim was the first in Denmark to participate in the clinical trial for Afamelanotide. How thrilling to hear he reports it worked perfectly, allowing him to be outside and pursue activities he longed to do, including golf. Additionally, it was a proud moment to see the link his father sent us of Joachim being featured on their national television network. Joachim is an advocate for those with EPP and for that we are fortunate. To have hosted him made our world larger and our hearts grateful. While writing this article, the FDA approved the drug Afamelanotide for use in the US, no doubt making the outlook for people with EPP brighter. Maybe one day Joachim will return to the States and together we can enjoy a bit of golf and, of course, grab a burger.

FASHION FORWARD

APF member, Claire Richmond, began the warm weather months longing to feel free from the restrictions of her port, which is necessary for her regular Panhematin infusions. As it turns out, displaying her true fashion sense was a state of mind that she decidedly overcame. Claire realized that “CONCEALING MY PORT AND SCARS IS LIKE HIDING SOMETHING I AM PROUD OF BECAUSE IT WILL MAKE SOMEONE



Claire Richmond



Ashley Noland



Megan Parrish



Nicole Castellano

ELSE UNCOMFORTABLE.” A quick Facebook survey revealed that she was not alone. Claire led her acute Porphyria friends to openly show their devices and feel comfortable in their summer clothing.

FIND YOUR SHADOW 2019 – THE MCKILLOP FAMILY

The McKillop family, led by EPP Shadow Jumper Morgan (age 9), was awarded the Find Your Shadow trip of 2019. Here is a review of their experience and how they enjoyed a trip...despite the sun!

“We arrived at our resort in the Animal Kingdom and were blown away by the beautiful villa and being able to look at the safari animals right in the backyard! This allowed us to experience Animal Kingdom, the sunniest park, on our own terms throughout the trip. We started our first park day off meeting up with our tour guide, Meagan, who was fantastic! We decided to head to Hollywood Studios. This park is where Morgan had a severe flare up last time we attempted Disney. Meagan was able to get us into and out of rides faster, spending less

time on the reflective pavement We felt like royalty! Meagan was so educated and constantly aware of Morgan’s EPP. She made sure Morgan was safe. When the sun did come out, we were prepared with an umbrella, in addition to her long sleeves, hat, and gloves, all provided by Shadow Jumpers via SOLUMBRA. And nothing will beat 7:00pm-ish every day when the sun would go down and Morgan could change into a t-shirt and shorts as we kept park hopping into the night.

Thank you so much to Shadow Jumpers for sending our family to Disney! They educated us on how to leverage our meals and indoor rides to avoid as much sun as possible until the evening time. Every EPP family should apply for next year’s FIND YOUR SHADOW because it was really something we’ll talk about forever.



**STAY TUNED FOR
FIND YOUR SHADOW 2020
INFORMATION AND APPLICATION!**

Many of you may not be aware that the APF has been assisting patients and doctors around the world since day one. In fact, we have helped patients in 74 countries. Since I received most of the international calls, I was aware of the lack of medical care for patients globally. My dream to create a worldwide program has now been realized and funded by a special grant so no monies are taken from the APF.

First, when we are contacted, not only do we send educational material to both the patient and doctor, we also put them in touch with a Porphyria expert to consult with the physician. In addition, we identify leaders and create patient groups around the world. With the inception of our APF Porphyria International Support & Education Group on Facebook, locating patient and leaders has become easier.



It has long been established that patients communicating with other patients is a powerful tool to improve health. This group has also helped patients find other patients in their respective countries. That is the first step in facilitating support groups and ultimately patient organizations. Right now, we are working with patient leaders in Mexico, Pakistan, Turkey, Chile, Jamaica, Poland and Russia. Other countries are in line for our assistance. Although it is challenging to work across the many language barriers and cultures, we have been very successful and are growing exponentially.

Recently, I had the opportunity to visit with a number of groups during my own personal travels and was happy to work while touring. If you are an international friend and want to be involved, please FB me or reach out to lyonapf@aol.com.

There are lots of opportunities to help one another. Pakistan members, Abduhl Waheed Butt and Ibadullah Khan Barcha recently met with Desiree to share friendship and CEP experiences.

GLOBAL GENES PATIENT ADVOCACY SUMMIT



ists and patients dedicated to help the rare disease community. The keynote speaker kicked off the event with a presentation entitled “Brain on Fire: My Month of Madness from Susannah Cahalan.” She spoke with exquisite detail and raw honesty. You’ve got to get her book as Porphyria patients can really re-

This year I had the wonderful opportunity to attend the Global Genes Patient Advocacy Summit 2019. They had well over 1,000 caring and dedicated physicians, scien-

late. Some of the Highlights for me were to listen to Chasing Cures: The power of Patients. David Fajgenbum, Co-Founder & Executive Director of the CDCN, inspired patients to always be alert and be invested with the relationship with your medical care team. The Protection Regulation: Implications for You and Drug Development and Finding Answers: The Importance of Communicating with Clinicians sessions were fascinating. I will be sharing and writing steps and hints and illustrations from the 2-day session in the coming weeks. When I left this event, I was inspired to help Porphyria patients to continue getting better testing, diagnosis, and treatments. To see this information on the APF Purple Light Blog, please join at <http://blog.porphyrifoundation.org> ~ Amy Chapman

Porphyria Poem by Jessica de Groot

I have a fear
that takes my life away
Friends, family, and joys
It leaves me crying and sick
Sick of life and always not being able to
do things
Always getting poked
in and out of the hospital
The fear can ruin my life
Letting the darkness eat away at me
But do I let it
It depends right
Sometimes it will rush in unannounced
taking away all my joys
But it will never be able to take
My future
My future is mine

Mine to hopefully enjoy
To see friends and family
To be able to do things in my life
Life won't bring me all sorrow and pain
Life will bring happiness and toughness
My fear is the pain
The pain that might one day take over
me
Make me addicted to things
Making me sick for way too long
I am scared of it
It leaves me all alone
It will make me push everyone away
I am scared it will leave me all alone
To deal with it all alone
Letting the darkness eat me whole
My fear is my sickness
Porphyria



The Global Porphyria Advocacy Coalition held an inaugural meeting in Milan, Italy on Sept 7. The constitution and by-laws were voted on, Porphyria organizations across the world joined, and the first Executive Board was elected. Sue Burrell (President, UK), Sean Hegarty (Vice President, Australia), Peder Sorenson (Secretary, Denmark) and Joaquin Montoto (Treasurer, Spain) will serve a two-year term. Five working groups were formed focused on Awareness, Education, Research, Medicines Access and Support. These groups are diving into the hard work of the global umbrella group. Kristen Wheeden will lead the Awareness working group and Desiree Lyon will lead the Medicines Access working group. The APF contribution will be invaluable in these roles.



REMINDERS

from the porphyria experts

1 FLU SHOTS

Flu shots are not contraindicated for individuals diagnosed with acute Porphyria and can be taken safely. Any immunizations appear to be okay. In fact, since other illnesses can bring on an acute attack, remaining healthy is one of the most important ways to prevent acute attacks.

2 CAT SCANS

There has been no information to date to suggest that CAT scans with or without contrast agents should not be performed on an individual with acute Porphyria.

3 ORGAN DONATION

Organ donation would be up to a transplant program or network. In acute Porphyrias any organ should be acceptable except the liver. A person with an Acute Porphyria should not donate their liver.

PORPHYRIA GRAND ROUNDS AT VANDERBILT UNIVERSITY

Dr. Sam Silver, Assistant Dean for Research at University of Michigan Medical School, delivered a talk to over 400 doctors at Vanderbilt University on the biochemistry, clinical presentation, diagnosis and treatment of the Acute Hepatic Porphyrias. He discussed the new investigational mRNAi drug, Givosiran. He also met with hematology faculty and fellows and talked about their patients with Porphyria, including those with PCT. Thank you, Dr. Silver, for furthering Porphyria education!

CEP LIVE WEBINAR

The American Porphyria Foundation hosted a CEP Patient Education and Support Meeting via online webinar on Tuesday, August 27, 2019. Patients had the opportunity to virtually meet fellow APF members who share similar experiences with Porphyria and participate in a presentation and Question and Answer session with Porphyria Expert, Dr. Angelika Erwin. Topics discussed ranged from blisters and infections to hair growth issues and light. This interactive event was a first for many of the patient members involved - and it was delightful to have had this opportunity. To the patient members who attended, thank you for taking the time to join us for this educational event.



BRITISH PORPHYRIA FOUNDATION 20TH ANNIVERSARY FESTIVAL

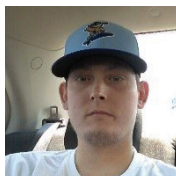
Our friends across the pond held a day-long festival highlighting their 20th anniversary. The day was attended by two hundred family, friends and caregivers. The APF will turn 40 soon ... we are gathering ideas for a grand celebration and look forward to *your* input.



MEMBERSHIP ADVISORY BOARD

The APF is pleased to announce the addition of a Membership Advisory Board to broaden and enhance membership services. In support of the work that our Board of Directors and Scientific Advisory Board are doing, the Membership Advisory Board will be on the frontline working to bring new ideas and initiatives that will serve our ever-expanding membership. This Board will also help support the APF to maintain our standard of excellence in serving those who turn to us for help. We welcome the Members of the Membership Advisory Board:

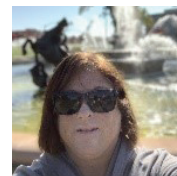
Sean Albright*, Jennifer Beck, Michael Boone*, Amy Burke, Valerie Burke*, Candace Colbert*, Milton Cubas*, Sharon Dill, Barbara Haskell*, Mike McGirr, Victor Mejias, Karen Warren, and Terri Witter*. (*pictured)



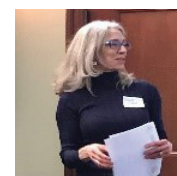
S. Albright



M. Boone



V. Burke



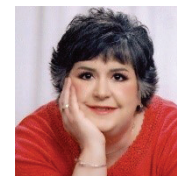
C. Colbert



M. Cubas



B. Haskell



T. Witter



INTERNATIONAL CONGRESS OF PORPHYRINS AND PORPHYRIA (ICPP)

The bi-annual ICPP congress was held in Milan, Italy, September 8-11. This conference is attended by physicians, researchers, patient advocacy groups, pharmaceutical companies and others interested in the latest scientific information related to the Porphyrins. A concurrent Patient Day offered the opportunity for patient/physician interaction and patient empowerment. The APF had four abstracts accepted, and Dr. Bruce Wang, Porphyria Expert, UCSF won the award for best presentation at the conference!



INTRODUCTION TO DRUG AND DEVICE LAW AND REGULATION FOR PATIENT ORGANIZATIONS

FDLI brings together law, industry, and FDA experts with deep advocacy experience to equip patient organizations with an understanding of the legal framework and strategies available for interacting with the agency. Kristen Wheeden attended the November 5-6 program to ensure that the APF is equipped to represent our community with the most recent avenues of engagement. Agenda Highlights Included: New Drug Development and Clinical Trials Regulation, Submission of Marketing Applications and the FDA Approval Process, Expanded Access, Implementation of the 21st Century Cures Act, and Interacting with Drug and Device Development Industries and FDA.

RARE DISEASE LISTENING SESSION



The APF held a listening session at the FDA at the end of August. A listening session gives the opportunity for patients to speak directly to FDA reviewers. The APF worked tightly with the FDA to ensure that appropriate staff would be present. Our objective in holding a rare disease listening session was to help the FDA understand the impact of living with Porphyria as a whole and as eight separate and distinct diseases, to differentiate between the two main categories of Porphyria (Acute and Cutaneous) and the burden of these diseases, and to convey the patient and/or caregiver experience of living with Porphyria. We had seven patients speak about their experience after a presentation from Dr. Amy Dickey. Feedback from the FDA was positive – once again, we are getting our voices heard at the highest level.



ADVOCATE IN ACTION!

The EveryLife Foundation held a “Rare Across America” opportunity for advocates to meet with members of Congress while they were in-district back in their home states. Rare Disease Legislative Advocates could speak for their rare disease as well as ask them to join the Rare Disease Congressional Caucus. Diana Ijames, APF member, met to introduce EPP and the treatment Scenesse with Senator Roy Blunt’s staff, Senator Josh Hawley’s staff, and Congressman Jason

Smith’s staff. “I have lived with EPP for nearly 49 years and I was part of the first clinical trial for Clinuvel. Never give up!” is Diana’s advice to fellow advocates. (Photo: Diana Ijames, center, Senator Hawley’s office)

TOD RIDES FOREVER

It is over 40 weeks since my beloved, Tod Teeple, “crossed over.” Here I now sit with days to go to before I race in the Iron-



man Cozumel to raise money for Circle of Friends For the Dying and The American Porphyria Foundation...

The rule I placed in front of me was that I could jog in place if I needed to but I was not allowed to ever stop. I stood and choked back heavy tears as I made that promise to my love. It is now 13.5 weeks back for me and 1.5 weeks to go until race time for Ironman Cozumel.

The best way to express the faith that both Tod and I had even in the middle of the worst storm we ever experienced and the deepest sorrow I have ever known, was written by a Christian singer recently on the loss of his son:

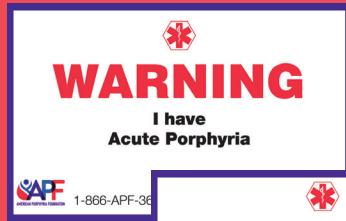
“We don’t follow God because we have some sort of under-the-table deal with Him, like, we’ll follow You if You bless us. We follow God because we love Him. It’s our honor. He is the God of the hills and the valleys, and He is beautiful above (and beyond) all things.” - Toby Mac

On November 24th I will toe the Ironman Cozumel race line in honor and deep love for my beloved Tod and the beautiful God we serve that saw fit to bring us together giving me the greatest love I have ever known. TOD RIDES ... FOREVER.

~ Lauren Warren

NEW RESOURCES FOR YOU:

WARNING CARDS The APF has designed updated Warning cards for the Acute Porphyrias, EPP, CEP, and PCT. Please call our office to have one mailed to you today!



LOCK SCREENS

This image can be saved to the lock screen on your smart phone for easy access by paramedics or medical personnel in an emergency. (Special thanks to members Colin McEwen and Rebekah Gidley!)



STARS OF HOPE

The APF recently received several boxes of beautifully painted stars from the employees at Alnylam Pharmaceuticals. Stars of Hope is a healing arts program designed to empower patients through beautiful designs and messages of hope. We will be distributing the stars throughout the year to our members. Give us a call if this is of interest to you and we'll be glad to send one your way or to someone you love while supplies last.

WELCOME IANY SCHNIEDER

Who's that kind voice at the APF when you call...It's Iany (pronounced Yan-ee)! Please extend a warm welcome to her as our APF Administrative Assistant. Iany started at the APF at the end of August and has been a quick study in all the work that we do. If you need a warning card, physician education packet, patient education packet, donation information...or just want to say hi, you can reach her on iany@porphyriafoundation.org, 866-APF-3635 or on Facebook as Iany Schneider at [facebook.com/ianyapf.mcdonald](https://www.facebook.com/ianyapf.mcdonald).



BEN MOLLIKA'S INCREDIBLE SENIOR PROJECT



An envelope of checks arrived at the APF office several weeks ago with a lovely note that the donations were part of a senior project. We had to know more! After contacting 18-year-old Ben Mollica, we learned that he held a fundraiser in coordination with his senior project, a research paper about current treatment options for Cutaneous Porphyrias. Ben teamed up with his grandpa Joe Mollica and their iconic local family business, Varsity Club, in Columbus, OH, to raise funds. "I learned a lot about Scenesse, which I'm very excited about it being approved. I'm glad that I could do something to help my community and would do it again! It was simple to do and had a strong impact on a lot of people," said Ben. Best of all, Ben had fun learning more about Porphyria, and his EPP – a disease that he and his grandpa share. Thank you, Ben, Joe and Varsity Club!

IN MEMORY & IN HONOR

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

IN MEMORY:

Arleen Lucus, Amy Stevenson, Vincent Barbera, Kathryn Lloyd, Lorrie Duda, Carol Anderson, Mr. & Mrs. Milroth, Kathleen Toelkes, Robert Zieles, Rosanne O'Connell, Katherine Feczko, Richard O'Neill, Pamela Edwards, Albert Feczko, Amy & Mike Zieles for **Grace Ann Feczko**; Mr. & Mrs. Coletta for **Donald Pierce**; Dorothy L. Gehrke for **Mr. Lorain Gehrke**; Jackson Williams for

Sharion Nichols; Kathleen A. Giacobbe for **John H. Giacobbe**; Barbara Baldwin Petersen for **Kimberly Baldwin**.

IN HONOR:

Varsity Club, Corey Brewer, Lisa Wang, Jennifer Marshall, Deborah Segor, Deborah Pryce, Kenneth Mollica, Amie Goode, Judith Murphy, Samuel Porter, Suzanne Wade Mercer, Samantha Durakovic, Anita Mollica, Mary O'Brien, Amanda Sigg, Sharlyn Mollica, Tracie Fishking, Scott Stricharczuk, Andrea Adler, Carolyn Prince, Robert Mer-

cer, Constance Middendorf for **Ben Mollica**; Mr. & Mrs. Dossin for **Peggy Dossin**; Ms. Grace Oshin for **Andrew Turell**; Ms. Mary Donnelly, Eric Gray for **Ralph Gray**; Michael Dickey for **Fred Jones**; Mr. & Mrs. Aitchison for **Brady Wheeden**; Mr. & Mrs. Long for **Jennifer Long**; Mr. & Mrs. Bucher for **Minnie Bucher**; Mr. & Mrs. Phillips for **Dr. Karl Anderson**; Elaine Sasso for **Elizabeth Britton**; Jennifer Ewing for **Desiree Lyon**; Phyllis Liddell for **Paul Kraft**; Julian Seidenberg for **Becca Barrett and Family**; Mary J. Hutson, Tom Graber for **Terri Witter**.

The information contained on the American Porphyria Foundation (APF) Web site or in the APF newsletter is provided for your general information only.

The American Porphyria Foundation does not offer medical advice, diagnosis, or treatment. Individuals should seek medical advice only from qualified healthcare professionals. If you think you may have a medical emergency, call your doctor, go to the emergency department, or call 911 immediately.

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SUPPORT THE APF

Please remember to update your Membership and Contact Information, including changes to your mailing address, as well as email you that you can continue to receive the APF's weekly Porphyria Post.

Please support the American Porphyria Foundation today. When you support the APF, you are making a contribution to an organization that provides solid medical information, hope and essential support to those affected by porphyria.

» Our Annual Fund enables the APF to maintain our physician and patient education programs, as well as many other services.

» The **Protect the Future** campaign was established to attract and train the next generation of doctors and specialists in the field of Porphyria. Over the next decade, we will lose *ninety percent* of our valued Porphyria experts. These men and women have led Porphyria research, testing and treatment for the past 30 years. Without financial support, we run the risk of losing knowledge of the disease, quality testing, diagnosis, and treatment, *and ultimately a cure*.

» You may also choose to honor a friend or loved one with your donation, or to remember someone with a memorial gift.

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AMERICAN PORPHYRIA FOUNDATION



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