



IMPORTANT PANHEMATIN® UPDATE



We are pleased to report that Recordati Rare Diseases Inc. has launched the new 350-mg single-vial dosage strength of PANHEMATIN® for the treatment of recurrent attacks of Acute Intermittent Porphyria. This is the first major change for this product that was originally approved by the U.S. Food and Drug Administration (FDA) in 1983. The new vial strength replaces the previous 313-mg vial at the same price! This new dosage strength more accurately reflects the dose required to treat most patients with AIP in this country. It also increases the number of patients potentially eligible for treatment with only one vial per day. There is a new labeling format, but the distribution process for Panhematin will stay the same. In addition, a new co-pay assistance program for PANHEMATIN® was made available starting in July 2017.

This program can help eligible patients with their co-pay when they receive PANHEMATIN® on an outpatient basis. The APF has sent a letter regarding this change to over 2500 physicians across the U.S. that treat Porphyria. The APF is pleased with the ongoing effort of Recordati Rare Diseases Inc. to serve those with Porphyria. "For more than three decades, physicians have relied upon as the only PANHEMATIN® FDA-approved treatment indicated specifically for patients with acute intermittent porphyria," said Paul Stickler, Vice President of Commercial Operations at Recordati Rare Diseases. "By making the dose needed for most patients available in a single vial, the new 350-mg dosage strength of PANHEMATIN® may make treatment of this devastating and painful disease less burdensome, thus addressing the needs of patients, physicians, and healthcare systems."

APF PRESIDENT'S AWARD



Congratulations to the Cook family, sons Cason and Caul, mom LeeAnn and dad Chris are the recipients of the 2017 President's Award. The Cooks are longtime supporters of the APF and heroes to all porphyria people. Their awareness efforts began in their hometown, Vernon, Texas by holding an annual Hat Day event in the schools. For the past two years, they have hosted a Barrel Race to benefit awareness, especially for EPP. The Cooks are a family to be admired and honored, not just for what they have done for the APF but because they are a loving family who are respected in their community.

BE COUNTED!



"How many people have your disease?" is one of the most often asked in the rare disease community. The American Porphyria Foundation wants to make sure there is an accurate answer to that question. The APF staff works hard to confirm our member database is updated and that each patient for each type of Porphyria is counted. Please contact the APF office if you would like to double-check that you are in the official database. Take the opportunity to say "hello!" to Edrin – and he will update your information. Not only will you be counted, but you will be sure to receive all the latest news and information from the APF. **Call 1-866-APF-3635 today!**

PATIENT DAY AND SCIENTIFIC CONFERENCE



The American Porphyria Foundation and the Porphyrias Consortium will host a Patient Day and Scientific Conference January 12-14 in Orlando, FL titled, "Heme Biosynthesis and the Porphyrias: Recent Advances." Patient Day will be held on Saturday, January 13 from 10am-5pm. The day will offer you the opportunity to learn directly from Porphyria experts and to gain valuable insight into your disease. You will also have the chance to socialize and meet new friends in the Porphyria community. The Scientific Conference will span all

three days. All are welcome to register, while physicians can earn continuing medical education credits. Attendees will learn about the latest advances in the diagnosis and management of the Porphyrias. Distinguished physicians from around the world will present their latest research and knowledge at clinical and research sessions tailored to each type of Porphyria. **Stay tuned for more information including registration and conference details!**

PATIENT EDUCATION MEETINGS



The APF hosted a Patient Education Meeting at Camp Sundown in Craryville, NY on July 21st. Guests joined camp families to learn about Porphyria and ask questions of Porphyria expert, Dr. Manisha Balwani, who skyped from Mount Sinai in New York City. Dr. Balwani was generous with both her time and expertise. Special guest and New York local Dr. Maureen Poh-Fitzpatrick was on-site to answer questions and share her knowledge. It was a special event that gave

the New York area Porphyria community an opportunity to learn and meet other porphs! Each guest was met by a Camp Sundown Counselor and offered a tour. Babysitters were even on hand so that parents could listen to the valuable information. Our previous meeting was held in Santa Rosa Beach, FL in May where patients were treated to the expertise of Dr. Karl Anderson. We are blessed to have a dedicated team of physicians who lend their time to Poprhya education to patients.

Pictured: Andrew Turell, Hannah Watkoske and Dr. Maureen Poh-Fitzpatrick/Presentation.

Upcoming Patient Education Meetings: Contact the APF if you would like to host a meeting near you!

Anaheim, CA: September 16, 2017 * Bethesda, MD: October 22, 2017 * Daytona, FL: February 10, 2018

PATIENT ADVISORY COMMITTEE

The APF relies on our membership to guide us in our mission and specific programs. The Patient Advisory Board is comprised of patient members from varied types of Porphyria. Our recent meeting on July 18th with our set of members brought great feedback from the committee along with specific action items to explore. Thank you to the Patient Advisory Committee members for participating in this important work: Michael Boone (AIP), Ruth Bruno (AIP), Amy Rose Burke (PCT), Sharon Dill (VP), Nicole Kirby (AIP), Ron Mayer (EPP), Victor Mejias (EPP), Benjamin Stratz (VP).

NEW FACEBOOK SUPPORT GROUP FOR CEP

The APF has launched a new Congenital Erythropoietic Porphyria (CEP) closed Facebook group to link CEP members. We have heard from members that it is difficult to make connections with other members living with CEP as there are only approximately 124 known cases worldwide. Now Abduhl Butt, who hails from Pakistan, Justin Hamilton and his wife Holly from the USA,

and Fede from Spain can connect on issues related to CEP. This change was made to differentiate CEP from the other forms of cutaneous porphyria given the specific nature of this rare disorder. We hope this offers our members with CEP the opportunity to connect and learn from each other. You can access this group through the Facebook icon on the APF website: www.porphyrifoundation.org. Click on "APF fb Support Groups" from the column on the left. The website administrators will monitor the group to add individuals and to ensure appropriate discourse. Please contact Edrin Williams at the APF office for additional support.

EPP DELAYED DIAGNOSIS SURVEY

The APF and the Icahn School of Medicine at Mount Sinai offer a big thank you to the patient community for your critical participation in the recent survey on EPP delayed diagnosis! Over 125 responses were received in a short period of time. The information that you provided will give the team at Mount Sinai, as part of the Porphyrias Consortium, a great sample to analyze. The purpose of this survey was to understand the path to diagnosis so that we will be able to increase awareness in the group of physicians most likely to see potential EPP patients.

THE FUTURE OF EPP KIDS FDA PHOTO CAMPAIGN

In a further effort to gain FDA approval of Scenesse and to educate the FDA on the pain and suffering EPP patient's face, the APF implemented a children's photo campaign. Development Director, Kristen Wheeden, initiated a crusade to collect photos of children living with severe reactions to the light. We collected many powerful photos and letters that described the impact of living with EPP. Some photos were of children suffering a reaction while others

showed the protective clothing required to endure venturing outside. The letters spoke of the daily effect of EPP and the impact a treatment would have on their lives. We want the FDA to hear our voices loud and clear that we are still here, still struggling, and want immediate approval of Scenesse/Afamelanotide 16mg. The children are our future – we will keep implementing new ideas until all people suffering with EPP have a treatment!





WHAT WE KNOW FROM BORDEAUX: INTERNATIONAL CONGRESS ON PORPHYRINS AND PORPHYRIA 2017

The ICPP 2017 was held in Bordeaux, France June 25th-28th, 2017. From Patient Education Day through the entire Scientific Congress, the gathering of scientists, clinicians researchers and patients in Bordeaux was an enormous success. The conference opened with a Patient Day themed, "TOGETHER WE ARE STRONGER." It was a wonderful opportunity for patient advocacy groups from around the world to meet and share information. Three Q&A Sessions (EPP, Acute Hepatic Porphyrins and Cutaneous Porphyrins) were held in the afternoon that featured a moderator and an expert panel. Each session was very well- attended and our own Desiree Lyon Howe successfully led the session focused on Acute Hepatic Porphyrins. The Scientific Congress featured over thirty lectures across three days. Sessions focused on Fundamentals on Heme Biosynthesis in relation to Porphyrins, Acute Intermittent Porphyria, Bullous Acute and Chronic Porphyrins, Erythropoietic Protoporphyrins, Clinical Complications of the Porphyrins, Clinical Evaluation and Laboratory Investigations in the Porphyrins and Miscellaneous and Emerging Therapies in the Porphyrins. The conference offered a tremendous opportunity for porphyria experts and physicians across the globe



to collaborate and share research. We are grateful for their participation in this bi-annual conference.

Pictured: Dr. Robert Desnick / Dr. John Phillips, Dr. Karl Anderson and Dr. Samuel Silver/ ICPP Attendees

BORDEAUX PATIENT PERSPECTIVE: RON MAYER My younger sister and I both have EPP.



We were officially diagnosed in 2011 (at ages 39 and 38) after my sister's online searching led her to the American Porphyria Foundation's website where she read EPP patient stories and immediately identified with their plight of pain and suffering. In 2012, we were both selected to participate in the FDA's Phase III trial for Scenesse. I received the placebo, but she received Scenesse. She said that for the first time in her life, she was able to experience daily life "as a normal person." She said it was transformative and hopeful. At every turn of this journey, I've come to realize "Knowledge is Power" and the key for us as patients. With this in mind, I attended the *International Porphyria Congress* recently held in Bordeaux, France. I spent the

full four days listening to bio- molecular chemists, geneticists, and Ph.D.'s of all varieties to learn more about our disorder, all with the hope of learning how I might become more effective with promoting a cure. What I came away with as a patient was twofold; first, scientifically understanding the disorder and the resulting pain allows me to better explain it, when I better explain those two things I get more interested listeners. Secondly, the negative psychological effects of living with EPP are extremely important to understand. Effectively treating the trauma, shame, isolation, and depression we experience should be a major battle cry for any drug, sunscreen, or gene therapy being promoted with the regulatory agencies. We each can play a part...write, read, make a call. Remember, nothing is going to happen while hiding in the shadows, we must get out. - Ron Mayer

FIGHT THE STIGMA! Have you ever been called a drug-seeker? A vampire? Has anyone told you that you are just crazy or that this disease is all in your head? We have heard countless times over many years that the stigma associated with those living with porphyria is demeaning. We have even heard that some of our members avoid treatment from health care professionals and that they don't seek much needed support from friends and family. The perception of patients living with porphyria won't change unless we help to make a change in the mindset of our communities. As a step, let's focus on physician education. We need to provide a better understanding of the Porphyrins for our physicians to identify and manage the patients better. Be honest with your physician about the stigma you face and ask your doctors to spread the word about Porphyria in their professional communities. In fighting this reduction in negative experiences for our patient community, it is our hope that demeaning and unproductive behavior will end. That's where YOU come in. Join the fight. Educate. You have a voice. Let it be heard.

We are Porphyria Strong. Contact the APF to learn more today.

#PORPHYRIASTRONG

THE PURPLE LIGHT BLOG Developed by Amy Chapman, APF Director of Social Media, The Purple Light Blog is a valuable tool to learn about living with Porphyria. The space was created to offer ideas, tips, and information you can find the scoop on APF activities, research opportunities, medical updates, and even APF merchandise. Amy works hard to write information that will benefit readers and says "what I have enjoyed most is interviewing our members, seeing their needs, challenges, their positive outlook despite having a porphyria disorder. This encourages others and gives them hope." Information is based on posts, talking with members, watching the needs of the groups and the many activities that the APF is spearheading. The blog is dedicated to all Porphyria patients worldwide. Check it out! <https://porphyriafoundation.blogspot.com/> Pictured: Amy and Craig Chapman



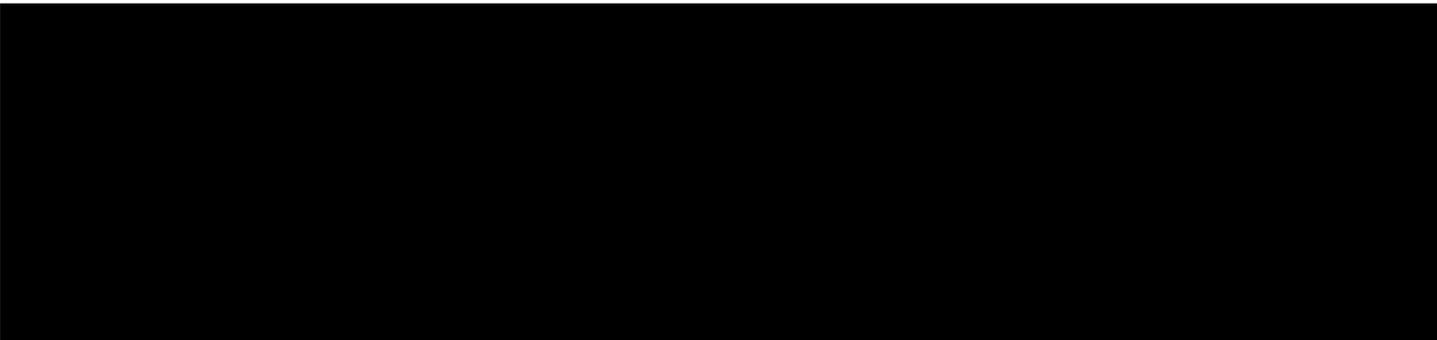
LEGISLATIVE UPDATE The APF participates in regulatory and legislative activities in Washington, DC to represent the needs of individuals with Porphyria on a national level. Some of the issues that we are monitoring include the OPEN Act, 340B Program, FY2018 Budget, DRG coding and insurance assistance. We are also working to understand the impact of the newly appointed FDA Commissioner, Dr. Scott Gottlieb. Here is an update on the DC organizations in which we are involved and some of the activities that relate to Porphyria.



NORD The National Organization for Rare Disorders (NORD) is an independent nonprofit organization representing the 30 million Americans with rare diseases. The APF participates regularly in member webinars, calls and meetings to stay in touch with public policy issues affecting our membership.

EVERYLIFE FOUNDATION The EveryLife Foundation is dedicated to accelerating biotech innovation for rare disease treatments through science-driven public policy. Kristen Wheeden, Director of Development, has joined the Community Congress Regulatory Working Group which is focused on improving the drug approval process at the FDA and on educating patients about the clinical development process.

RDLA and THE RARE DISEASE CAUCUS The APF participates in the Rare Disease Legislative Advocacy (RDLA) activities. The RDLA promotes the Rare Disease Caucus which is a forum for Members of Congress to voice constituent concerns, collaborate on ideas, facilitate conversations between the medical and patient community and build support for legislation that will improve the lives of people with rare diseases. Kristen has participated in previous meetings and will continue to represent the APF. The RDLA also hosts Rare Disease Week which will take place the week of February 2018. It is an opportunity each year to storm Capitol Hill to discuss issues affecting the rare disease community. Interested in joining? Contact the APF office. **ULTRA RARE STRATEGY CALLS** The APF participates in weekly calls devoted to healthcare policy issues affecting ultra rare diseases. Connect 4 Strategies bridges patient groups, industry and regulators with the issues affecting patient groups that have a low prevalence. A "rare disease" affects 200,000 or fewer individuals. Ultra rare conditions affect in the hundreds or thousands.



PLEASE DONATE TO THE AMERICAN PORPHYRIA FOUNDATION

Funding supports...

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MEET DR. ASHWANI SINGAL, MD, MS, FACG, FAASLD We are honored to have Dr. Singal



as a renowned porphyria expert. Dr. Singal is an Associate Professor of Medicine and Co-Director of the UAB Porphyria Center in the division of gastroenterology and hepatology at the University of Alabama at Birmingham. After completing medical school at the University College of Medical Sciences, Delhi University, India, Dr. Singal completed a residency at the Mount Sinai School of Medicine, a gastroenterology fellowship and Masters in Clinical Sciences from UTMB Galveston, TX, and a fellowship in transplant hepatology from Mayo Clinic Rochester, MN. Dr.

Singal is board certified in transplant hepatology, gastroenterology and Internal Medicine. In addition to English, Dr. Singal's practice supports Hindi and Urdu. During his gastroenterology fellowship at the UTMB, Galveston TX, he became very interested and involved in managing porphyria patients with Dr. Anderson, as a *Protect the Future* physician. He had an opportunity to join the ongoing clinical trial comparing phlebotomy and low dose HCQ in PCT. Dr. Singal's interest in treating patients with Porphyria has continued, saying "When one is working closely with these patients one understands and realizes that unlike so many other medical diseases, Porphyria has a lot of emotional and social issues along with physical effects. I like to manage and help these patients to the best of my abilities. This has provided me with an opportunity of clinical translational research in Porphyria, with the NIH funded Porphyrias Consortium, and closely working with international experts and learning from them." Dr. Singal and Anjna, his wife of 28 years, have 2 children, a son and a daughter. His hobbies include travel, watching movies, walking, and listening to music. The APF is thrilled to know this brilliant physician and to offer his expertise to our members.

JOIN PORPHYRIA RESEARCH. If not you...then who??

Living with a rare disease is hard work every single day – and our researchers are working hard to better understand our disorders and find treatments. They can't do it without our participation in our own future.

RESEARCH STUDIES These research studies need participants!

- Longitudinal Study of the Porphyrias (all Porphyrias),
- Panhematin® in the Treatment of Acute Attack of Porphyrias (AIP, HCP, VP)
- Effect of Oral Iron Therapy on Erythrocyte Protoporphyrins (EPP)
- Harvoni Treatment for Porphyria Cutanea Tarda (PCT) *NEW STUDY*

HOW TO PARTICIPATE Contact the APF office on 1 -866-APF-3635. We will connect you with the closest Porphyria Center OR coordinate participation remotely in research studies. The APF works together with the whole research team at all the Porphyria Centers.

RECENT PUBLICATIONS These publications were made possible as result of your participation.

June 2017: Clinical, Biochemical, and Genetic Characterization of North American Patients with Erythropoietic Protoporphyrinemia and X-linked Protoporphyrinemia

<http://jamanetwork.com/journals/jamadermatology/article-abstract/2629997>

June 2017: Acute Hepatic Porphyrias: Recommendations for Evaluation and Long Term Management

<https://www.ncbi.nlm.nih.gov/pubmed/?term=Acute+Hepatic+Porphyrias%3A+Recommendations+for+Evaluation+and+Long+Term+Management>

June 2017: Hepatitis C Treatment in Patients With Porphyria Cutanea Tarda

<https://www.ncbi.nlm.nih.gov/pubmed/28641714>

PORPHYRIAS CONSORTIUM The Porphyrias Consortium is focused on expanding knowledge; developing new strategies and methods for diagnosis, treatment, and prevention of illness and disability resulting from the porphyrias. Access the website <https://www.rarediseasesnetwork.org/cms/porphyrias/> to learn more about current research and participating clinical research centers.

PROTECT THE FUTURE Our *Protect The Future* campaign was established to attract and train the next generation of doctors and specialists in the field of Porphyria. They work directly with members of the APF Scientific Advisory Board as part of a rigorous program of study, clinical and laboratory work, research and publishing. Please let the APF know if you would like to donate directly to this important program!

DO YOU NEED INSURANCE HELP? If you are experiencing a problem with insurance for your needed treatment, please contact the APF office. There are options and we are happy to help. For the last decade our members have experienced increased concerns particularly with treatment for the acute porphyrias. Insurance companies are not always paying for Panhematin® treatment properly. One reason is that hospitals are contracting with insurance companies and forcing treatment for patients only on an outpatient basis, even when they are very ill. The APF is aware of these issues and has solutions to our members.

PORPHYRIA AWARENESS SURPRISE! Congratulations to APF member, Megan Parish who received a marriage proposal at a TV station while filming a story on porphyria. Congratulations on the proposal and on her successful porphyria awareness effort. What a great lesson to be promoting awareness wherever you go. Watch and enjoy!



<http://www.thv11.com/news/local/ark-woman-battling-rare-blood-disease-visits-thv11-to-spread-awareness-gets-surprise-proposal/460154628>.

PROFILE IN COURAGE: JENNIFER BECK The APF presents Jennifer Beck as our most recent *Profile in Courage* member. Jennifer has endured great pain while managing her EPP. She has created a community that helps her to manage her condition, in addition to advocating for approval of Scenesse in the USA. Most recently, an article was printed that showed her church services being held without lights to accommodate her at worship. Here are Jennifer's words on the importance of advocacy and how she has focused her efforts: Hi, my name is Jennifer Beck. I'm 48 years old and live in Connecticut. I'm writing today about self-advocacy. As we endure the



journey of EPP, we must remember that we can help others along the way. I find in helping others it gives me hope and lifts my spirits so that I can face another day. I recently experienced a drastic intensification of my symptoms of EPP. I am now intolerant of all artificial lights in addition to the sun. This has affected every part of my life and my family's life. If helping other adults doesn't move you strongly, consider the children who need this treatment. Or maybe you could build up your anger and use that energy for advocacy. How shameful of the FDA to tell me to go to Switzerland for treatment when they won't approve it here. Clearly the FDA thinks the treatment would be OK for me to pursue on my own. What is their role in slowing this process? Why are they holding it up? I find that to be reckless, careless and cruel. Here are action steps we all can take to move toward approval: Call the FDA, Write the FDA, Make a sample letter for all of your friends and family and coworkers and church members to send, Email the FDA, and Contact your senators!

COLIN MCEWEN'S WORDS ON LIVING WITH AIP... One of the (many) weird things about having a chronic illness is you no longer have sick days. The days of being "sick" and napping, watching movies and doing nothing start to disappear as you learn to do more while being "sick". Your endurance for activities while feeling "sick" grows, your medication is no longer there to make you better rather it's there to make you better at life while "sick". You stop whining and complaining because everyone, including yourself, get tired of hearing about it because you are sick every day. What doesn't change is feeling "sick" and knowing you're "sick". Sure, there are



days when it's really bad and you just can't do anything but because you are well-practiced, somehow you find a way to still be somewhat productive. The only time you truly get a "sick" day is when you are hospitalized but you come to fear and loath the hospital so much you don't dare go willingly or while conscious. So yeah, I miss a good 'ole fashioned "sick" day. #raredisease #Porphyria #complaining #bootstraps. Take a look at Colin's interview on living with Porphyria. Colin, along with Rose Jeans, paint a picture with their voices on what it is like to live with Porphyria. <http://www.alnylam.com/patients/porphyria/>

SKYLER PARIS, OUR "WARRIOR" APF member Skyler Paris is living up to the meaning of his name as he recovers from his May 11 liver transplant. He celebrated his 17th birthday on August 13th from his hospital bed at Monroe Carroll Children's Hospital in Nashville, Tennessee. With his dedicated mom Brandy Paris by his side, Skyler is estimated to remain at the hospital for an additional 4-6 months when he will move on to a bone marrow transplant. Please send cards and letters to Skyler at: P.O. Box 331191, Murfreesboro, TN 37133. Your love and support mean the world to him! Financial support can be offered through his [gofundme.com](https://gofundme.com/skylerstransplants) account at <https://gofundme.com/skylerstransplants>. Keep up the fight, Skyler!



APPRECIATE YOUR HEALTH CARE PROVIDERS "Nurses dispense comfort, compassion, and caring without even a prescription. " ~ Terri Guillemets



Meet APF Member, Layla Puckett, age 8. Layla had a recent medical experience where both an esteemed Porphyria expert and a caring nurse were by her side. Dr. Sylvia Bottomley arranged the appointment and personally stood by to make sure it was a success. Then nurse, "Nana" Lana McCoy, took care of her with a loving and kind-hearted hand. These beautiful photos are a reminder of the difference providers can make in a health care experience. Each day across all the Porphyrias, we rely on healthcare providers to manage our care. We are sick and may be scared and they are busy and hard at work. It only takes a moment to offer a smile and a simple, "Thank you!"

GARY EYSTER ART STORY Have you ever wondered why you see this photo on the APF website and on the APF Facebook support group pages? Meet esteemed artist Gary Eyster. Mr. Eyster was an APF donor for many years as a close friend of art broker and APF member, Ralph Gray. Upon his death in July 2013, he donated his life's work and entire collection of art to the APF. Specializing in abstract expressionism, his work has received many awards and honors. Interested in owning a print? Visit www.garyeyster.com – go to "Galleries" and choose your favorite. We thank Gary for his generosity and we are pleased to be able to offer his magnificent art to our membership.



PATIENT WORTHY We are pleased that the APF website was used to help diagnose and support little Nora, featured in this article "Fun in the Sun? How One Little Girl Beat the Summer Heat after an EPP Diagnosis." This story tells of the diagnostic odyssey that Nora and her parents endured to find the culprit of her pain. Their pediatrician referred them to the APF website which has become a great resource for them as well as many other patients. <https://patientworthy.com/2017/07/18/fun-in-the-sun-with-epp/amp/#>



JESSICA'S WHITE COAT DAY! The white coat ceremony marks the beginning of a journey toward a career in healthcare. We are excited to share that our own Jessica Hungate recently received her white coat. We wish Jessica great luck as she dives into her studies at Texas Tech University in El Paso, TX. The APF community is supporting you!



WEDDING BELLS Lelia Dodson married Ron Polly recently in Montecito, CA with a host of family and friends to celebrate. The APF was a family affair for Lelia, daughter of APF Executive Director Desiree. Since age nine, Lelia has helped with everything from folding APF brochures to stamping envelopes. She continued her volunteer efforts by assisting with major projects like facilitating FDA meetings, negotiating grants and initiating and naming the Protect the Future program (PTF). Lelia and her family continue to help the APF. Husband Ron even assists with legal questions, while Desiree's grandkids I to R, Charlotte, Miller, William and Elizabeth fill in when needed.

IN MEMORY AND IN HONOR We thank the families and friends who honored their loved ones with a generous gift to the APF. Your donations will help to support the many programs we offer to our members.

In Memory: Mary Lou and William Rickert for **Gina Marie R Opperman** ; Gary Horn for **Sandra Horn**; Kelly Thompson for **Kevin Wiggins**; Mark Smith, David and Victoria Snide, Rose Lilly, Joyce E Falkenbury for **Donald McLean, Jr**; Teresa Adams for **Tiffany Kilcrease Hooten**; Sheila and Richard Meltabarger, Michael L Hammond, Leonard and Marianne Nethers for **Ingo Lehmann**; Kathleen Toelkes for **Donna Pagano**; Charlotte J Beck for **Elva Denger**.

In Honor: We also thank those who honored a friend or family with a generous donation to the APF. Anne Johnson, Vincent Poleo for **Candace Johnson Mesa**; Greg Young for **Tracy Godsted Nudo and Suzie Young**; Debra Clark for **Noelle Lombardo**; Christine J Stilo-Ison for **The Lombardo Family**

If you would like to donate to the APF "In Memory" or "In Honor" of a friend or loved one, please contact the APF office at 1-866-APF-3635.



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

The APF does not give medical advice or engage in the practice of medicine. The APF under no circumstances recommends particular treatments for specific individuals, and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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What's New at the APF

www.porphyrifoundation.com

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

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

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

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