



AMERICAN PORPHYRIA FOUNDATION

1st Quarter, 2018

SCIENTIFIC CONFERENCE AND PATIENT DAY SUCCESS IN ORLANDO, FLORIDA

The **Heme Biosynthesis and the Porphyrins: Recent Advances Scientific Conference** was held January 12-14, 2018 in Orlando, Florida. The conference was co-hosted by the Porphyrins Consortium, the Genetic Disease Foundation and the American Porphyria Foundation. An international expert faculty was brought together to discuss the advances in our understanding, management, and treatment of the hepatic and erythropoietic porphyrias and the latest research on heme biosynthesis. The three-day symposium was attended by over 130 physicians, investigators, and trainees. Day one focused on the opportunity to learn about the eight major porphyrias. The faculty of experts discussed the genetic and biochemical defects, unique pathophysiologies, clinical manifestations, medical management, and current and emerging therapies. A highlight of the day was the patient interviews that were conducted after instruction about each type of porphyria. This offered the trainees an opportunity to learn firsthand from the personal experiences of patients – and to understand the impact on patient’s daily activities and quality of life. Day two and three were intensive days of research presentations by expert faculty. The goal was to expose young faculty, medical fellows, and doctoral trainees to the recent advances in heme biosynthesis and the porphyrias. A poster session was held that outlined two dozen research projects in the porphyrias. The APF had our own poster to highlight our work. Check out the poster from the APF on Page 3! We offer much appreciation to the international faculty of leading experts in this field that are working hard to advance research and to improve the lives of people impacted by porphyria. In addition, many thanks to Hetanshi Naik, Senior Genetic Counselor and Project Manager, of the Porphyrins Consortium along with Edrin Williams and Amy Chapman of the American Porphyria Foundation for their hard work in organizing a successful conference.



THE PORPHYRIAS CONSORTIUM



SCIENTIFIC CONFERENCE CLINICAL DAY PATIENT INTERVIEWS

Several APF members took on a major role in educating physicians and researchers on the impact of living with porphyria. After training on each type of porphyria, they then had the opportunity to learn first-hand. Patients were interviewed by a porphyria expert then answered questions from the attendees. We thank them for their brave and honest interviews!



AIP patient: Amy Chapman
Interviewer: Dr. M. Bissell



PCT patient: Diana Biegler
Interviewer: Dr. K. Anderson



CEP Patient: Justin Hamilton and Holly Hamilton (wife)
Interviewer: Dr. R. Desnick



EPP patient: Olivia Monaghy and Marianna Monaghy (mom)
Interviewer: Dr. M. Poh-Fitzpatrick

PATIENT DAY ORLANDO Saturday, January 13, 2018



Fifty patients from the US and Canada gathered down the hall from the scientific conference for a packed day-long patient meeting. Drawing from the clinical and research experience of international faculty along with practical experience from APF members – participants were treated to over ten presentations followed by Q&A sessions with an expert panel. The morning session was dedicated to a porphyrias overview, genetic information, and the erythropoietic porphyrias. The afternoon session focused on research, the acute porphyrias, and caregiver/support information. Effective current and emerging treatments for all the porphyrias were presented. We thank our expert faculty co-chairs for leading the discussions: Dr. E. Minder, Dr. S. Keel, Dr. D.M. Bissell and Dr. C. Levy. The day also featured three APF members who discussed issues of importance.

PATIENT DAY SPEAKERS

Along with fantastic presentations and Q&A sessions delivered by expert physicians, these APF members supported patient day with eloquent presentations:

Jason Marcero (X-Linked Porphyria)

Jason discussed his transition from defense to offense in his fight with Erythropoietic Protoporphria. His presentation was inspired by his interest in studying porphyria and his journey to his current research. Jason is a PhD student at the University of Georgia in the Department of Biochemistry and Molecular Biology.

Sandra Boone (Caregiver – Acute Intermittent Porphyria)

Sandra presented on the role of the caregiver as the “other part of the porphyria patient” and the importance of taking care of yourself while you support the patient.

Sharon Dill (Variegate Porphyria)

Sharon gave an inspiring talk on the importance of participating in research. Her message focused on the possibilities of research and overcoming the obstacles to engage in research studies.



Dr. M. Bissell



Sandra Boone



Morning panel: Dr. Keel, Dr. Balwani, H. Naik, Dr. Phillips, Dr. Minder, J. Marcero



Afternoon panel: Dr. Badminton, Dr. Levy, Sharon Dill, and Dr. Wang

RESEARCH STUDIES

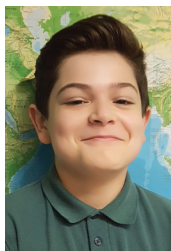


Are you ready to participate in a research study? Here is a chart of current study opportunities:

Title	Longitudinal Study of the Porphyria (LS)	A double-blind, randomized, placebo-controlled, parallel group trial on the efficacy and safety of Panhematin™ in the treatment of acute attacks of porphyria	Clinical Diagnosis of Acute Porphyrias	Therapeutic Studies in Porphyria Cutanea Tarda	Erythropoietic Protoporphrias: Studies of the Natural History, Genotype-Phenotype Correlations, and Psychosocial Impact	Effect of Oral Iron Therapy on Erythrocyte Protoporphyrin Levels in the Erythropoietic Protoporphrias	Newer Direct-Acting Anti-Viral Agents as Sole Therapy of Porphyria Cutanea Tarda in Subjects with Chronic Hepatitis C
Brief Description of Study	An observational study looking to learn more about the natural history of all the porphyrias	This is a clinical trial, comparing Panhematin to glucose to determine the effectiveness of Panhematin as treatments for acute attacks	This study will look at the number of abnormal lab tests and porphyria-like symptoms in family members of patients with acute porphyria	This study will compare the two treatments for PCT, phlebotomies and hydroxychloroquine	This is an observational study, similar to 7201, which is looking more in depth at patients with EPP	This is a clinical trial, giving EPP patients a standard dose of iron pills for one year to see if it helps improve their symptoms and decreasing protoporphyrin levels.	This is a clinical trial, giving PCT patients with hepatitis C a standard dose of Harvoni to see if it also resolves the PCT symptoms
Who can participate?	All porphyria patients (adults and children) with a confirmed diagnosis	Acute porphyria patients with recurrent attacks (adults)	First degree relatives of patients with DNA confirmed acute porphyria, who have not had DNA testing yet (ages 15 and up)	PCT patients (adults)	EPP patients (adults and children) who are in the Longitudinal Study (7201)	Adult EPP patients who are in the Longitudinal Study (7201) and have a low ferritin level	Adult PCT patients who also have hepatitis C
How to get involved?	CALL THE APF ON 866-APF-3635 TO BE CONNECTED WITH THE COORDINATOR OF THE SITE						

ARE YOU PARTICIPATING IN PORPHYRIA RESEARCH? REMEMBER... COMPLIANCE IS CRITICAL!

PORPHYRIA SPEECH WINS 6th GRADE CLASS PRIZE AND OUR HEARTS



The APF recently received an amazing donation in the amount of \$13.00 on behalf of Ms. Kara's Speech and Debate Class in Tampa, FL. For their final assignment, students were to choose a charity and write and perform a persuasive speech. The student who won would have every student's dollar donated for that charity. The winner, Griffin, has a mother living with porphyria. He made an amazing and heartfelt speech. Griffin Vasquez's chose to write his speech about his mom, Breanne, who lives with Acute Intermittent Porphyria. Thank you, Griffin! You are an inspiration.

Griffin's full speech: A Cause For Hope (unedited)

How many of you all know what porphyria is? Well, it is a blood disease that people can get that affect them badly. The American Porphyria Foundation helps people who have this blood disease. This disease is very rare for people to have. Most of the time, doctors do not know what is wrong with the people who have this disease. Jackie Cory, a member of this foundation, says that since she was five, her hand, face and knees were getting puffy. So, later on when she was in Junior High, she went to the doctors. She was still having problems and the doctors did not know what was wrong. Then they gave her basic shots and allergy pills. This story hits home to me because this is the same thing that happened to my mom. The doctors did not know what was wrong with her for years! It all started in 2008 when I was only 3 years old. My mom went to the hospital and got diagnosed with pneumonia. Unfortunately, they took half of her lung out of her body. Later on, she had bad breathing problems that she suffered from. Several years later, after more tests and MANY more doctors, we found out that she had porphyria. In the summer of 2017, she went to the hospital because she had an infection in the remaining part of her lung that continued to get worse over time. Since that summer, she has been in and out of the hospital over repetitive infections. The doctors then proceeded to remove the rest of her half-lung because it was badly infected. So, my mom has one lung now. Today, my mom is in a rehab facility that takes care of her a lot and is helping her recover from the surgery she just had. Why I wanted to tell this story is because the people that are affected by this disease are in pain physically and mentally. Not to mention the bills, that adds up. This foundation helps these people. Many people donate to this foundation and it can help people's lives. Every dollar you donate can help a person's life and their family. Please donate to this foundation on behalf of my mom and my family. Thank you.



FREE GENETIC (DNA) TESTING AND GENETIC COUNSELING

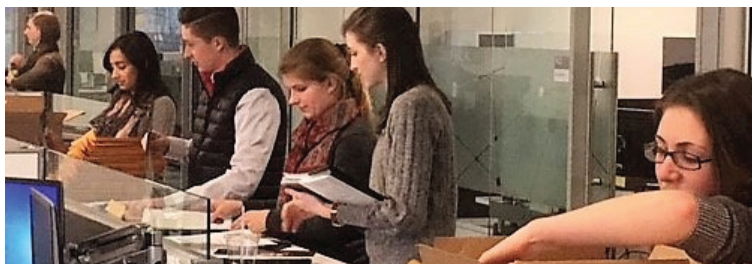
Alnylam Pharmaceuticals is offering third-party genetic testing and counseling programs for the acute hepatic porphyrias at no charge. What is genetic testing? Genetic testing can tell a person if they carry a mutation in a gene associated with a predisposition to, or diagnosis of, an acute hepatic porphyria and can be performed regardless of whether a person is currently experiencing attack symptoms.

Who is eligible? Patients must be at least 16 years old and meet eligibility criteria including elevated PBG OR unexplained recurrent prolonged episodes of severe abdominal pain AND two of the following: red to brownish urine, known or suspected family history of AHP, blistering skin lesions on sun-exposed areas, peripheral nervous system manifestations occurring around the time of abdominal pain, central nervous system manifestations occurring around the time of abdominal pain or autonomic nervous system manifestations occurring around the time of abdominal pain.

How do I order genetic testing? The test MUST be ordered through your physician who will also be the only person to receive results. Contact the APF for more information and for a packet to be sent to your physician.

What is genetic counseling? Genetic counseling is a service that provides information and support to people who have, or may be at risk for, genetic diseases.

How do I receive free genetic counseling? Individuals who have a diagnosis of acute hepatic porphyria, have a known family history, or who are undergoing a clinical evaluation and and potential genetic testing for an AHP for genetic testing through InformedDNA. Available in the US only. Contact the APF for more information.



Employees at Alnylam Pharmaceuticals prepare materials to educate physicians on the genetic testing and counseling programs it supports.

GIVOSIRAN PHASE 3 CLINICAL TRIAL

Do you have an acute porphyria diagnosis, elevated PBG and more than two attacks per year? You may be eligible to participate in the Givosiran Phase 3 clinical trial. Givosiran is an investigational RNAi therapeutic developed by Alnylam Pharmaceuticals for the treatment of acute porphyrias (AIP, VP, HCP and ALAD). This treatment is subcutaneously administered and targets ALAS1. The Phase 3 trial is a randomized, double-blind, placebo-controlled study in more than 20 countries to evaluate the efficacy and safety of Givosiran in approximately 75 patients. Travel will be paid for those eligible for participation.

Contact the APF to be connected with a participating research site!

ALAD PORPHYRIA (ADP)



ALAD porphyria is an extremely rare disorder with few cases reported in medical literature. Most cases have occurred in Europe; however, the disorder can potentially occur in any population. At present, there are nine patients identified worldwide. ALAD porphyria is a genetic metabolic disease characterized by almost complete deficiency of the enzyme delta-aminolaevulinic acid (ALA) dehydratase. Deficiency of this enzyme leads to the accumulation of the porphyrin precursor ALA, which can potentially result in a variety of symptoms. Symptoms vary from one person to another, but usually come from the neurological and gastrointestinal systems. This disease is inherited as an autosomal recessive disorder. More males have been identified with ALAD porphyria than females, but the disorder probably affects males and females in equal numbers. Researchers suspect that some cases of ALAD porphyria go undiagnosed or misdiagnosed, making it difficult to estimate the true frequency of this disorder in the general population. The onset of ALAD porphyria is usually during infancy or childhood, but late-onset of the disorder has also been reported. Milton Cubas of Miami, FL is the first identified patient in the western hemisphere. Dr. Karl Anderson (University of Texas Medical Branch, Galveston, TX) made his diagnosis through biochemical and DNA methods. We are pleased to share Milton's story below.

RECORDATI REIMBURSEMENT SUPPORT AND PATIENT ASSISTANCE PROGRAM

Panhematin® is a treatment for the acute porphyrias (AIP, VP, HCP, ALAD) manufactured by Recordati Rare Diseases. It is the only commercially available heme therapy in the United States. This important patient assistance program was developed to help patients who experience issues with access to treatment and offers comprehensive assistance for insurance-related issues. This is a free service available to patients, caregivers, medical billing staff, healthcare providers, and others who have questions about insurance coverage and reimbursement related issues. Contact 866-209-7604 to access this program OR the APF office for additional information. This program can assist with issues such as:

- Benefits investigation
- Insurance counseling
- Claims support
- Prior authorizations/appeals
- Copay assistance
- Patient Assistance Program
- Reimbursement support
- General Inquiries

CLAIRE RICHMOND Founder, Hello and High Five



Claire, who lives with AIP, is a testimony to overcoming adversity to reach new success. She has worked hard to not let her medical diagnosis dictate her future. Instead, faced with a job loss, Claire has found success with the creation of a new line of greeting cards for athletes. You can read more about Claire here: <https://businessrecord.com/Content/Opinion/Opinion/Article/Guest-Opinion-Jobless-but-not-hopeless-a-business-is-born/168/963/80912>

<https://businessrecord.com/Content/Opinion/Opinion/Article/Guest-Opinion-Jobless-but-not-hopeless-a-business-is-born/168/963/80912>

MEET MILTON CUBAS, APF Member and ALAD Porphyria (ADP) patient



My name is Milton Eduardo Cubas and I am 29 years old. I am studying at Miami Dade College to become a math teacher. When not working hard at school, I enjoy sports and physical activities.

My first porphyria attack was on a very hot summer day in Cartagena, Colombia. I remember feeling fatigued. I drank a whole bottle of water, assuming I was dehydrated. But once I got in a taxi I felt nauseated and still fatigued. I wasn't able to eat, only vomiting water. We searched for a diagnosis in Colombian hospitals, but they had no answers. I remember feeling a lot of pain while looking for anyone to tell me what was going on. We cut my trip to Colombia short because my pain was getting worse.

Once home, we went to Miami Children's Hospital and my attacks got better. Still, my doctors couldn't find what was happening to me. I would have an attack every month or two for a year until a doctor named Elsa Vasconsuelos told me that I may have Porphyria. Soon after, my dad found Dr. Anderson of the University of Texas Medical Branch. I took two or three trips to Galveston, Texas, until he diagnosed me in February 2003 with aminolevulinic acid dehydratase-deficient porphyria, which is abbreviated as ADP. Through my teenage years, I had attacks nearly every month. Once I hit my 20's the attacks spread out more. The longest I've spent without an attack is two and a half

years, but after that I had three attacks close to each other.

My last attack was mid-July of 2017. To prevent attacks, I get hematin treatment every Friday. I tried spacing out the hematin to every 10 or 14 days, but I would have an attack. During the attack, I would have to be hospitalized to get daily hematin for four days. I receive my heme treatments in an infusion center.

I have had both positive and negative experiences with this condition. Some nurses don't know how to administer the hematin the correct way when I'm hospitalized. The neuropathy affects me every day from dressing to doing homework. I have trouble extending my fingers that stops me from making hand gestures. I have foot drop and can lose my balance easily. In the summer, I can't tolerate sun for long.

There have been positive experiences, too. I've met a lot of wonderful people, nurses and doctors who have helped me. My family has supported me and helped me when I couldn't drive or when I was hospitalized.

I want to be a Math teacher and am studying hard to graduate. I also want my hands to get better, so I do physical therapy as often as I am able. For people who have Porphyria: Knowledge is Power. The more you know about Porphyria the stronger you will be. It is also important to participate in research, and I am in the longitudinal study at UTMB.

NEW LOGO, NEW SWAG! APF MERCHANDISE



Check out all merchandise at porphyriafoundation.com under Publications and Products!

Please submit orders and payment to Amy Chapman on Amy@porphyriafoundation.org or 1-616-213-0030. Leave a detailed message including: Full Name, complete mailing address, phone number, and the item(s) that you would like to order by quantity & size. Payment can be made in an email or by phone with a Visa/MC Number, Expiration Date, & CVV code on the back of your card. NO CC info is EVER kept on file.



Long sleeve shirts:
Gray or purple,
Price Each- S, M,
L \$20.00 Each **
X-LG, 2XL, 3XL are
\$3.00 each more**



Long Sleeve Zip
Up Hoodie: Gray or
Purple, Price Each-
S, M, L \$45.00
Each ** X-LG, 2XL,
3XL are \$5.00 each
more**



Long Sleeve Pull
Over Hoodie:
Gray or Purple,
Price Each- S, M,
L \$40.00 Each **
X-LG, 2XL, 3XL are
\$5.00 each more**



Gray Soft Baseball
cloth hats
adjustable hat
backside - \$22.00
Each (Fits Adults
Sizes)



A NEW LOOK FOR THE APF!

After 37 years serving the porphyria community, the APF has a fresh new look. The new brand was developed with honoring our mission in a vibrant palette in mind. Member Sean Albright has already used it on his racing car (see photo)! Stay tuned for an updated website!



FIGHTING ISOLATION: PART II



Last time, I focused on tips and strategies for engaging with people who live close by. In our global world it is likely that many of your friends and relatives are hundreds or thousands of miles away. Long distance visits require more planning and communicating. The first communication must be internal – be honest with yourself and know what you can and can't do. Driving exhaust you? Consider travelling by plane or train. I have VP and I know it can be difficult, embarrassing to share with others the things you can't do – afraid that it will come across as being weak or worse yet, a complainer. So instead we opt out at the last minute or “suck it up” and endure unnecessary pain and exhaustion. Talk openly and honestly with the people you are spending time with. Let them know that while you may have to sit out on some activities, you don't expect nor want them to miss out nor do you need a babysitter (but if you do become ill, speak up and let someone know so they can help take care of you!) If possible, discuss the activities or events that everyone wants to do and then decide which ones you can do – depending on your body's cooperation. The day before a trip is usually a little hectic as we run last minute errands, do laundry, and pack, that we are often exhausted before we even start out! Try to do as many of these “last minute” activities a day or two sooner, allowing a “rest day” before leaving. Depending on the length of your travel, you might also need to plan to have light activities on your first day. Plan for the inevitable. Pack healthy snacks and drinks in your carry-on luggage. Never pack your medications in your checked luggage! Make sure you have more than enough to last you the duration of your trip. Whether it is a short overnight visit or a month-long trip, always, always have your medical information close by – at all times – that means out on the boat on the whale watch off Cape Cod, on the horseback ride in Wyoming, and at Disneyworld in Orlando. Let one of your travel companions know where this vital information is and how they can access it if needed. If you get preventative Panhematin or D5/10 infusions, speak with your physician about scheduling them before and after your trip to be most beneficial. Living with Acute Porphyria is a day to day challenge, sometimes that challenge is a struggle, and sometimes that struggle is a fight. Fights are best fought with others by our side; helping, guiding, supporting and encouraging. We all know what Acute Porphyria takes from us – don't let it take away those who want to fight the fight by our side.

RARE DISEASE WEEK ON CAPITOL HILL



RARE DISEASE WEEK ON CAPITOL HILL

Rare Disease Week on Capitol Hill will take place during the last week of February. The week brings rare disease community members from across the country together to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators. Edrin Williams (Director of Patient Engagement, APF) and Kristen Wheeden (Director of Development, APF) will lobby for porphyria by sharing with members of congress our need for access to medications, increased research, and effective treatment. The week will culminate with Rare Disease Day at the National Institutes of Health. Jointly sponsored by the National Center for Advancing Translational Sciences and Clinical Center at the NIH, Rare Disease Day at NIH aims to raise awareness about rare diseases, the people they affect and NIH research collaborations to advance new treatments.



AUSTRALIA HOSTS FIRST CONFERENCE

We are proud of Jessica Betteridge, President Porphyria Association, Inc. Australia, for the recent meeting held in Melbourne, Australia. The agenda was terrific as were the esteemed attendees. The APF mentored her both in Houston and weekly via FaceTime. We hope to have a similar arrangement with key individuals in porphyria groups worldwide.









HAVE YOU EVER WONDERED ABOUT THE WORK OF THE APF?

This poster, created for the scientific conference in Orlando, highlights the broad scope of work we do on behalf of our membership. You can view the full poster on the APF website at www.porphyrifoundation.org.

GET READY FOR PORPHYRIA AWARENESS WEEK APRIL 21-28, 2018



Porphyria Awareness Week offers participants an opportunity to choose from a wide range of activities to raise porphyria awareness among family, friends and in their communities. We strive to dedicate this week to promote this rare disease, reduce the stigma associated with this porphyria through education, and provide support for those affected. The APF will help by providing: porphyria brochures, PorphyriaLive DVDs, Porphyria fact sheets, PowerPoint presentations materials for medical seminars, and press releases for local newspapers and television. These materials written by our esteemed Porphyria Experts are invaluable to all involved in your care. Every effort to increase porphyria awareness is vital. This year, the APF has collaborated with international porphyria groups on a unified approach by designating International Porphyria Awareness Week 2018.

-  **What can you do in YOUR community to create porphyria awareness? Here are some ideas:**
-  **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 illness.
-  **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 seminar, grand rounds on porphyria 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.
-  **Assist at medical conventions** or health fairs to educate laypersons and physicians on porphyria. Ask your hospital or doctor if there is a local meeting where you can hand out materials or tell your experience. Befriend your physicians, and they will share their newfound knowledge of the disease.
-  **Volunteer** your talents or skills to help achieve the educational programs of the APF. Interested in hosting a patient education meeting? Contact the APF today!
-  **Purchase APF Merchandise.** See the APF website for shirts and other APF products.
-  **Learn how to be an advocate** in your daily life and share your knowledge everywhere.

APF AMERICAN PORPHYRIA FOUNDATION

MEMBERSHIP
Membership Database - 9,000

12% OTHER
33% PHYSICIANS
55% PATIENTS

MISSION The APF is dedicated to improving the health and well-being of individuals and families affected by Porphyria.

PHYSICIAN EDUCATION PROGRAMS

PATIENT EDUCATION PROGRAMS

SUPPORT & ASSISTANCE PROGRAMS

PHORPHYRIAS CONSORTIUM (PC)

PROTECT THE FUTURE (PTF) PROGRAM

AWARENESS AND MEDIA

PATIENT ADVISORY COMMITTEES

RARE DISEASE ADVOCACY

LEGISLATIVE AND FEDERAL INITIATIVES

COMMUNICATION, SOCIAL MEDIA, PATIENT CONNECTION

RESEARCH SUPPORT

INTERNATIONAL SUPPORT

INDUSTRY SUPPORT

SCIENTIFIC ADVISORY BOARD

ACUTE INTERMITTENT PORPHYRIA (AIP)

ALPHA PORPHYRIA

CONGENITAL ERYTHROPORPHYRIA (CEP)

PORPHYRIA CUTANEA TENUIS (PCT)

HEPATOERYTHROPORPHYRIA (HEP)

ENTHEOPORPHYRIC POTOPORPHYRIA (EP) AND K-LAND

VARIEGATE PORPHYRIA (VP)

RESIDUAL COOPERATION (RC)

WWW.PORPHYRIAFUNDATION.COM | 866-APF-3635 | 4900 Woodway, Suite 780 Houston, TX 77056-1837

SHADOW JUMPERS

at www.porphyrifoundation.com/shadowjumpers

Head to the new kids SHADOW JUMPERS section on the APF website to check out...

How to apply to win a trip to Disney with LIGHT THE MOMENT 2018!

Name our EPP mascot!

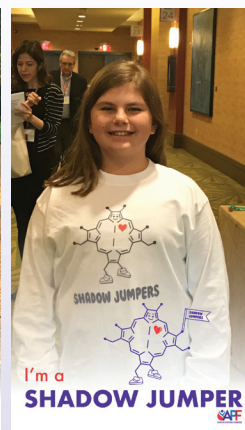
Learn Tips and Tricks for EPPers and send in your ideas to: shadowjumpers@porphyrifoundation.org



Madelyn, Age 12

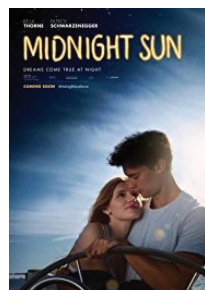


Brady, Age 12



Olivia, Age 12

Purchase Shadow Jumpers merchandise online



AWARENESS OPPORTUNITY! MIDNIGHT SUN (PG-13)



Midnight Sun is a drama about a girl living with Xeroderma Pigmentosum (XP). It will be in theaters on March 23, 2018. The movie centers on Katie, a 17-year-old sheltered since childhood and confined to her house during the day by a rare disease that makes even the smallest amount of sunlight deadly. Fate intervenes when she meets Charlie and they embark on a summer romance. The APF is planning awareness activities in coordination with the movie release about living with a rare disease marked by extreme photosensitivity. Stay tuned for more information!

IN MEMORY & IN HONOR

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

IN MEMORY:

Carole and Glenn Kuklewski for **Vincent Kuklewski**; Carole A. Cobbs for **Wilhelmina Harris Buster**; Eric Lifschitz for **Selma Lifschitz**; Davida Hansen for **Marge Thompson**; Cynthia MacNeil Sola for **John E MacNeil**; Veronica K. Dice for **Richard Dice**; Gloria R. Sheehan for **Paul Sheehan**; Susan K. Massey, Marcia and Eugene Williams, Brian Wetzel, Megan and Nathan Yeager, Sarah and Chris Farren for **Jon Klopfenstein**; Diane L. Levere for **Dr. Richard L. Levere**; Thomas W. Walsh for **Jane I. Walsh**; Linda C. Head for **Norman Campbell**; Victoria Gehm for **Judy Coley**; Michael and Carol Farina for **Vincent K. Farina**; Christopher and Elizabeth Peterson for **Judd Byrne**; Charlotte E. Wiedman for **Alice Ryback**; Residence of Shenendehowa Village for **Connie Wilson**; Shelby Jennette, Cindy Waters, on behalf of the English Department, Thomas Dale High School for **Donald N. Cox**; Charlotte Beck for **The MacKay Clan**; William and Marylou Rickert for **Gina Marie Rickert Opperman**.

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

IN HONOR:

Mary Frances Donnelly, William A. Gray, Myrna C. Cartledge,

Grayfred B. Gray, Arlene De La Mora, Lynne Murray-Gray, Ian Gray, Larry Pritchard, Gregory Diaz, K. L. Hanson, Ruth Wilson, Paula Hendrix, Sara Elaine Collier, JoLynn Foldesi for **Ralph Gray**; Sharon Dill for **Amy Chapman**; Sandra and William McHugh for **Chery Kosma**; Steve C Dossin, Ph.D., for **Peggy Dossin**; Charlotte Beck for **The McCoy Family**; Zila Reichman for **Dorit Reichman Ovadia**; Karol D. Webster for **Kim Bastian**; Linda Nagin for **Melissa Nagin**; Diana Parrish for **Megan Parrish**; Robert J. Fielitz for **Dr. John D. Phillips**; George J. Rusnak, Jr., for **Diana Sabella**; Jennifer R. Ewing for **Desiree Lyon Howe**; Margaret E. Whittenburg for **Jamie and Jocelyn Whittenburg**; Connie and Martin Helleson, Shirley A. Knodel for **Jennifer Streeter**; Tobina A. Aclaro for **Constance L. Romero and Edrin Williams**; Sonja Beck-Vertkin for **Stephanie Beck Feifs**; Patricia Green for **Clarissa Clark**; Maureen E. Curran for **Dr. Peter Tishler**; Susan Nuckols for **Camden Nuckols**; R. Thomas McFadden for **Kelly Carlson**; Dave Russell for **Craig and Nicole Leppert**; Andrew W. Altman, Brian Roeder, Shani Rosenzweig, Christopher Newman, David Strunk for **Craig Leppert**; Edward Leppert for **Nicole Leppert**; Kara Betourne for **Breanne Vasquez**; Elizabeth Ferry for **Stephen T. Ferry**; Melissa Gilmartin for **Gia Ventrice**; NBHS Class of 1984 for **Janet and Tich**; Greg Young for **Tracy G. Nudo and Susan Young**; Cheryl Harriman for **Jeffery Pradovic**; Anne Johnson for **Candace Johnson**; Halley Woodward for **Claire Richmond**; Rachel Wise for **Jere and Pauline Wise**; Susan and Fred Cerkoney for **Fred, Steph and Jason**; Dale Moczynski for **Alicia Moczynski**; Carole Gaudette for **Tristen Gaudette**.

The information contained on the American Porphyrria 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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