



Porphyria Awareness Week 2010: It's All About Our Members!

APF members did a dynamite job this year engaging local and national media, raising funds, and getting porphyria awareness into hospitals and medical schools. Thank you all! This is some of the great work you were a part of:

EPP Awareness 'round the SF Bay



Kim Moya's husband and daughter both have **EPP**. During Awareness Week Kim took her kids to Disneyland (see *Lessen the Sunshine*, p. 3), then she came home and got APF fact sheets out to all the family's medical providers. She also reached out to local media and her town's mayor. Kim sent us an update recently after talking to the news reporters: "They really want to learn about Porphyria! Yippee!"

Why We Need Panhematin

Amy Chapman spoke in Chicago in April to Lundbeck, Inc. employees. She addressed her history with **acute intermittent porphyria (AIP)**, difficulties with diagnosis, and her current regime, which includes regular Panhematin treatment. For nurses, pharmacists, physicians and drug company representatives, hearing about the disease from a patient's perspective can really help. You can read more of Amy's story inside on page 6 and on our website: www.porphyrifoundation.com/about-the-apf/member-stories/amy-chapman ...Continued on page 7



Porphyria Research Meeting

The Porphyria Clinical Research Consortium will meet at the Gordon Conference on the **Chemistry and Biology of Tetrapyrroles** at the end of July. This annual meeting is an important gathering place for physicians and scientists who treat and study porphyria, so the APF is also sponsoring attendance for several of the **Protect the Future** doctors who are working to become the next generation of porphyria experts.



This year, John Phillips, PhD, a **Protect the Future** grantee (here with Dr. Desnick (I), and Dr. Kushner), will present a paper at the Gordon. Dr. Phillips works with Dr. Kushner at the University of Utah and has published papers on PCT,

CEP, HEP and other porphyrias.

For porphyria patients, it is very important that doctors and scientists have a chance to discuss new information that may contribute to new modes of treating the diseases.

We need to hear from you!

The APF works very hard to update all members who have expressed interest in participating in clinical trials and the porphyria registry.

Please let us know: if you have moved, if your home or work email address has changed, or if your home, work or mobile phone number has changed.

Call or email us with updates at 1-866-APF-3635 (273-3635) or porphyrus@aol.com

Porphyria Research News and To Dos

The FDA has given the go ahead for **clinical trials** of the drug **Afamelanotide for EPP**. Some centers are already starting patients on the trial drug, and others will be in progress soon. If you have any questions or concerns, please call the APF. We're always happy to hear from you!

The **Porphyria Consortium Contact Registry** is up and running for all porphyrias! To learn more and find out how to join, please see the "Registry" link at the top of the APF website. The registry is a project of the **Porphyria Clinical Research Consortium** and anyone with porphyria is encouraged to join. Doctors and scientists need your participation to learn more about our diseases.

The contact registry is a way for patients to learn about clinical research opportunities. It is anonymous and free of charge. All data will be stored in a secure, computerized database. No personal identifying information will be given to anyone without your expressed approval.

The registry is not linked to APF membership, but we hope you will **join the American Porphyria Foundation** too! The APF has played an active and ongoing part in the porphyria **Consortium**, and supports porphyria patients and families through education, awareness and advocacy in hospitals, funding agencies and the media.

The National Institutes of Health recognized the importance of the patient advocacy groups in making us a part of the **Clinical Research Consortium**. With patients spread out all over the country it is important that we have an advocacy group to link us together. So please consider joining the **Contact Registry**, and thank you for continuing to be a member of the APF.

EPP Family in Hometown TX Paper



APF member **Lee Ann Cook** and her sons **Cason** and **Caul** were featured in an article in their hometown newspaper, the Vernon Daily Record (left) just in time for National Porphyrin Awareness Week. Both boys suffer from **erythropoietic protoporphyria (EPP)**. Lee Ann writes:

"Vernon is only about 11,000 people. I grew up here and then moved off to college. My husband and I have been here for 14 years! [After the article was published,] there were tons of people that said, 'I had no idea what all your boys had been through.' I wanted to get the word out and never really thought about how to do that until I read the newsletter and it suggested it in there. So thanks for the idea! And thanks for all you do!"

Thank You to the Cook family, for sharing your story and teaching your community about porphyria.



Lee Ann has also been engaged in an activity that too many families with porphyria find themselves involved in: appealing to her insurance company for coverage for the **Lumitene** she gives her boys to prevent pain and swelling (as Cason had after a day of snow skiing, left). She writes "it helps them tremendously! ... but [the insurance company has]

denied me twice already. I'm still going though!"

Have you had success with getting insurance coverage for **Lumitene**? Write and let us know, your experience could benefit others who are trying to accomplish the same thing.

Women with AIP Needed for Research!

The Mount Sinai Porphyria Lab is looking for women who have been diagnosed with acute intermittent porphyria (AIP) and have severe recurrent attacks, or repeated attacks associated with their menstrual cycles, to volunteer for research.

Volunteers will submit a small blood or saliva sample for DNA studies. Please call Dana Doheny, Genetic Counselor and Research Coordinator at the Mount Sinai Porphyria Lab at 212-659-6779 or 866-322-7963 with any questions about the study and to obtain instructions for collection and shipping of samples.

For additional information about AIP, or to have a Physician Information Kit mailed to your doctor, please call the APF at 866-APF-3635 (866-273-3635).

Do you have CEP?

If so, chances are you've never met anyone else with your condition. The APF would like to help bring CEP friends together to share your experiences and support.

Members with the more common types of porphyria have enjoyed the benefits of communicating with and even meeting others who share their diagnosis. If you have CEP and are interested in enjoying the fellowship that comes with meeting others, please contact the APF. Also, watch our website and the APF ENews for more information.

For those of you unfamiliar with **congenital erythropoietic porphyria**, it is also known as Gunther's Disease and is extremely rare, with fewer than 200 documented cases worldwide. Symptoms usually begin in infancy, although the disease can cause anemia even before birth. In less severe cases symptoms can develop in adulthood. Photosensitivity is extreme in CEP, causing severe blistering, scarring, and thickening of the skin. Cumulative blistering and scarring is sometimes severe enough that the extremities—fingers and/or facial features—can be damaged or lost through skin damage and infection. Heme production is either normal or increased in CEP, yet patients often require blood transfusions because the disease shortens the life span of red blood cells.



To assist in public and physician awareness of the disease, several of our members agreed to be featured in television programs and print media about CEP. Monica Firchow and her siblings maintain an outstanding website about their father, Gene Bennett, whose severe case of CEP was researched by porphyria experts trying to better understand the disease. The website is full of information about CEP and family photos, as well as Mr. Bennett's amazing story of hope and courage.

Despite disfigurement (he lost large parts of his face and fingers), Mr. Bennett somehow put CEP in its place and took on the challenges of daily life like a champion, supporting a wife and seven children, and eventually earning a small airplane pilot's license (above). To read his story and learn more about CEP, see www.genebennett.net

If you have CEP, would you like to tell your story for the APF newsletter and/or website? Many people read the APF website and newsletter and are interested in learning more about the disease and its impact on your life. Your stories are powerful, and can offer education and hope.

Please send them to the APF at porphyrus@aol.com

More research on CEP is desperately needed, but funding for this work is almost non-existent. To make a donation or raise money for CEP research, or to train a young CEP expert, please contact the APF. Donations should be marked "**CEP Research**" or "**Protect the Future**" for training.

Lessen the Sunshine at Disney

If you are photosensitive, the thought of standing in lines in the sunshine at an amusement park can be painful enough to make you stay at home. Disney parks now have a FASTPASS system that allows you to skip the wait by making a timed appointment at attractions. The service is easy to use and there is no additional charge.

FASTPASS Step-By-Step

Attractions that offer the FASTPASS have three lines: the regular standby line, a second line for booking your FASTPASS, and a third for entry with the FASTPASS at your assigned time. Attractions that offer FASTPASS entry have a lighted monitor at the entrance showing what FASTPASS appointment times are available.

To get your FASTPASS, insert your theme park ticket into the FASTPASS machine. You'll be given a one-hour window for your return. For example, if your FASTPASS return time is 10:05-11:05 a.m., you may not enter with FASTPASS before 10:05am, but can return for immediate entry any time between 10:05am and 11:05am.

On your scheduled return, go directly to the FASTPASS entrance and enter the attraction pre-show or boarding area with little or no wait.

There is no limit to the number of FASTPASS tickets you can get during the day, but you typically will not be able to get more than one at a time. When you get one FASTPASS ticket, it will show the earliest time you can get another.

Guest Assistance Card

Kim Moya took her three children to Disneyland during their spring break. Daughter **Carly** has **erythropoietic protoporphyria (EPP)**, and the family used the park's Guest Assistance Card to gain speedier access to all the rides and attractions. Kim writes:

"[The card is] really easy to get. All you do is go to the Town Hall as soon as you get into Town Square. Tell them that you need a Guest Assistance Card for your group. They will ask some questions about the person's limitations. They want to know if you can take stairs, how many are in your party (the limit is six) and how long you will be at the park.



"They write down all of the information and then give you the Guest Assistance Card stamped with the number in your party and a red arrow showing that you can go to the front of the line, or go in the ride exits instead of the entrances. Once you have the card, you can bring it back with you the next time you visit Disneyland, just bring the card back to Town Hall. They will ask about the size of your party and how much time you will be spending at the park. Getting the new card takes about half as much time as it did to get the initial card. I hope this helps!"

Thank You Clinuvel!

Clinuvel Pharmaceuticals has stepped in as a real champion for the APF in our online work. CEO, Dr. Philippe Wolgen (below) has been extremely supportive, directing the Clinuvel team to create a beautiful new website design for us. Clinuvel's Lachlan Hay and his Communications and IT Team have been extremely generous with advice and assistance in resolving technical matters for the website, as well as offering strategic perspective for our online presence.



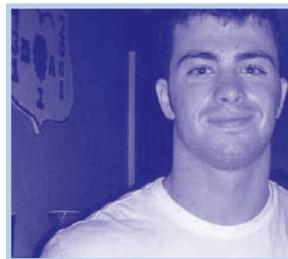
Clinuvel is the maker of **Afamelanotide** for photoprotection. It has already had very encouraging results in Europe. **EPP** patients are participating as volunteers for the clinical trials. We are happy to report that most of the U.S. patient volunteers are from our APF membership. The trials will take place over a period of four to five months. After the results are reviewed, the FDA will hopefully give it a seal of approval. The possibility has already inspired tremendous hope for patients after decades of living with few options but to remain indoors.

Afamelanotide trials for EPP are beginning now in the United States. If it proves effective and is approved for use, Afamelanotide would be only the second treatment approved specifically for EPP, and patients would have an alternative to Lumitene for protecting themselves from the sun. For the parents of young EPP patients especially, the possibility of a better life for their children is all they could wish for.

Thank you, Dr. Wolgen and the Clinuvel team, for the hope you have brought to families with EPP, and for your support of the APF mission to promote the well being of all people with porphyria.

Living in the Shadows with EPP

Craig Leppert and his sister **Nicole** both suffer from **EPP**. Craig started having symptoms as a baby, but was not diagnosed until he was five years old. Now 20 years old and a college student in upstate New York, he is hoping to participate in **Afamelanotide** trials, both for himself and his sister, but also for young children who are still growing up with the restrictions of EPP.



Craig and his mother, Tracy, spoke with the Syracuse University *Daily Orange* during Porphyria Awareness Week and Craig gave presentations on EPP in all of his classes.

You can read the *Daily Orange* article at www.dailyorange.com/news/living-in-the-shadows-su-freshman-struggles-with-sun-allergy-1.1427658#

Dr. Shedlofsky Educates in KY

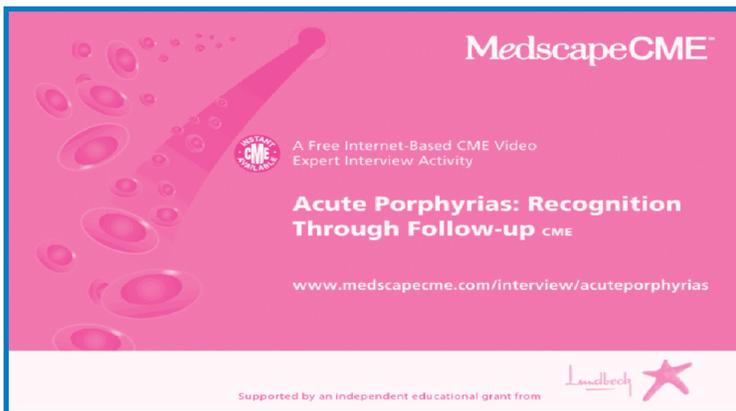
Dr. Steven Shedlofsky gave a Continuing Medical Education talk on May 4 in Paducah, KY. He spoke at Western Baptist Hospital on the **Evaluation and Management of the Porphyrrias**.

Dr. Shedlofsky first learned the porphyrias working with Dr. Herbert Bonkovsky (see **Protect the Future**, this page), just as Dr. Bonkovsky had first learned the porphyrias working in Dr. Donald Tschudy's lab at the National Institutes of Health. Dr. Shedlofsky now serves on the American Porphyria Foundation Scientific Advisory Board and is a porphyria expert himself. In addition to educating other doctors in his region, he accepts physician referrals for porphyria patients and advises local doctors in caring for their patients with porphyria.

Continuity between one generation of physicians and the next is a fundamental feature of all medical training. Doctors learn by working with others in the field while deepening their studies. With our **Protect the Future** program, the APF has created a setting for doctors and scientists in the U.S. looking to develop specialty knowledge of the porphyrias. This program is essential to preserving the knowledge base of our experts. It and the research projects of the porphyria consortium are a unique opportunity for porphyria patients and their families. We should make good on this opportunity by contributing to **Protect the Future**.

New Online CME Video

Acute Porphyrrias: Recognition Through Follow-Up



www.medscapecme.com/interview/acuteporphyrrias

Intended for hematologists, gastroenterologists, primary care physicians, emergency medicine physicians, obstetricians/gynecologists, and other healthcare professionals who may encounter patients with the acute porphyrias. Covers recognition, evaluation, treatment, complications, and prevention. Features expert physicians Herbert Bonkovsky, MD; Manisha Balwani, MD, MS; Brendan McGuire, MD, MS; Karl Anderson, MD.

This course fulfills one CME credit and is available for free and online. Find it and other resources for physicians on our website at: <http://www.porphyrriafoundation.com/for-healthcare-professionals>

Protect the Future

Dr. Bruce Wang and Dr. Ryan Caballes are both new to the **Protect the Future** program this spring. They join the group of physicians and scientists working closely with members of the APF Scientific Advisory Board to become the next generation of porphyria experts. These men and women are selected for their excellent academic credentials and an interest in the porphyrias. Dr. Wang (right) is a Fellow in Gastroenterology at University of California-San Francisco, and has worked closely with long-time APF board member and porphyria expert Dr. Montgomery Bissell since 2002.



Dr. Caballes is completing his medical residency at Farmington University Hospital in Connecticut, and working with porphyria expert and APF advisory board member Dr. Herbert Bonkovsky. Dr. Caballes is fluent in Tagalog and did some of his medical training in the Philippines.

The grant APF researchers won last year will do many things, but it does not include funding to train future experts. The APF—you and I—will need to look to ourselves and our families to raise those funds.

Here are three ways you can help:

- Speak with your own doctors and ask if they would like to participate in a conference call with an expert. If so, call the APF with your doctor's name and contact information and we will forward your doctor instructions for joining the call.
- Encourage your doctors to visit the APF website, where they will find **Emergency Room Guidelines for Acute Porphyrrias**, a **Safe/Unsafe Drug Database for Acute Porphyrrias**, and two free, one-credit **Continuing Medical Education (CME)** programs. (All doctors must complete a certain number of CME credits each year.)
- Help us train future experts through the **Protect the Future** program. Once you have renewed your membership, make an additional donation to the APF, and make a note that it is for support of **Protect the Future**.

If we fail in this, a time will come very soon when there will be NO porphyria experts practicing in the United States. If we allow this to happen, the ONLY people who will have been hurt will be You, Me and Our Families.

—Desiree Lyon Howe

**Let's Work Together To
Protect OUR Future**

Educating Laboratory Scientists



Dr. Elizabeth L. Frank is a scientist at the University of Utah Health Sciences Center and director of ARUP Laboratories in Salt Lake City, UT (a noted porphyria specialty lab). In April, she gave a well-attended talk on **Porphyryns and Porphyrias** via the online portal of the American Association for Clinical Chemistry.

The presentation was aimed at diagnostic laboratory scientists and focused on understanding

the heme pathway and how porphyrins can become toxic in humans and produce porphyria symptoms. This understanding is the basis for choosing and interpreting the lab tests that are used to diagnose the porphyrias.

Her talk concluded with a detailed flow chart for the diagnosis of all of the porphyrias. Moving from suspicion to testing to diagnosis for a specific porphyria depends on a few basic steps:

- understanding symptoms as acute (neurological) or non-acute (cutaneous)
- first-line testing for urinary PBG (acute) or total plasma porphyrins (cutaneous)
- advancing through an established testing protocol based on the results of initial testing to rule out porphyria or distinguish among the porphyrias and make the diagnosis.

Dr. Frank reminded her audience of the importance of **Rapid PBG testing** for acute porphyria, noting:

"If rapid PBG testing is available in your laboratory, it can be used to screen a sample from a patient with symptoms suspicious for an acute porphyria. A positive test is indicative of disease and the patient can be treated without delay. A negative result can be followed by collection of a 24-hour specimen for additional porphyrin analysis. Delayed diagnosis and treatment of an acute attack may result in permanent neurological damage and can be fatal."

Dr. Frank also co-authored an article in *Clinical Laboratory News, Porphyrias: A Guide to Laboratory Assessment* (M. Laura Parnas, PhD, and Elizabeth L. Frank, PhD, April 2010) www.aacc.org/publications/cln/2010/april/Pages/series.aspx

And she referred to a more complete flowchart for porphyria diagnosis that physicians may find helpful: www.arupconsult.com/Algorithms/Porphyrias

For information on the Rapid PBG Test Kit:
www.porphyrifoundation.com/testing-and-treatment/testing-for-porphyria/rapid-pbg-test

Awareness Is an All-the-Time Thing

Robert Dawson has his own take on the difficulties so many patients have with finding a diagnosis for a rare disease. He was diagnosed with **variegate porphyria (VP)** several decades ago, and his doctors often ask him to help train medical residents in the diagnostic process by telling them his story. Robert says he's happy to volunteer because he understands the importance of rare disease training and the challenge of finding new and interesting ways to humanize the porphyrias for practicing doctors.

Robert hopes that these young doctors will recall his experience, and that what they learn from him will enable them to help other patients to prompt diagnosis and correct treatment.

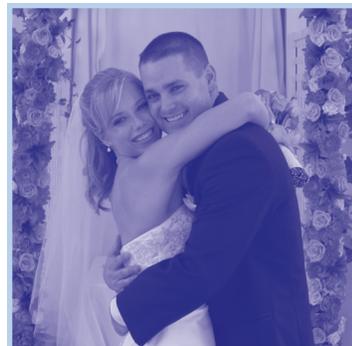
Acute porphyria can be a challenging diagnosis to make. Running tests for porphyria and analyzing the results both take practice, and most labs do not perform these tests routinely. Porphyria experts recommend sending test samples to a specialty lab like **ARUP** (see article, this page) or the **UTMB-Galveston Porphyria Lab** that has experience in evaluating porphyria test results, and of course the treating physician must first suspect porphyria and order the proper tests as outlined at left.

It's wonderful when porphyria patients can help others by educating physicians about the disease. A list of labs that do comprehensive porphyria testing is available on our website: www.porphyrifoundation.com/testing-and-treatment/testing-for-porphyria/us-porphyria-labs

High Hopes for New Treatment

Meghann Bauer has had symptoms of **erythropoietic protoporphyria (EPP)** since she was a baby, yet went undiagnosed until age 16.

Meghann says "I just never found the right way to describe my symptoms so that the doctors would think to test me for EPP." Meghann remembers running her hands under cold water constantly as a child. Without an explanation for her symptoms, summer meant constant pain, and she recalls falling asleep covered in ice packs every night.



Pediatricians even told Meghann's parents to take her to a psychiatrist. Luckily, the psychiatrist assured them that there was nothing wrong with their daughter emotionally and that something physical was clearly causing her pain.

Since she was diagnosed, Meghann takes **Lumitene** to help with her symptoms. When she does have flare-ups, she uses motrin and darvocet for pain, and packs on ice.

Today, Meghann is looking forward to participating in clinical trials of **Afamelanotide**. She is hopeful that this may be a way to "help my husband and I do the things we enjoy, such as boating, swimming in our pool, picnics, and walking our boxer puppy."

Bringing Disease Reality to Drug Maker



APF member **Amy Chapman** and her husband Craig spoke to employees at **Lundbeck**, maker of **Panhematin**, in April. They spoke about the reality of **acute intermittent porphyria (AIP)** for a patient who from early adulthood has been stricken with attacks

of pain, nausea, weakness and most frighteningly, paralysis in her legs. Since Amy began receiving Panhematin treatment a few years ago and now depends on it to bring her attacks under control, she understands the importance of communicating the human need for their product to the company that makes Panhematin.

As Amy tells her story on the APF website:

For years before my diagnosis, I was sick every three weeks on average. I would go to the doctor and receive medicine, but nothing worked. I had severe stomach pain, muscle pain, and nerve pain; I had nausea and headaches; I couldn't remember things and was nervous; my blood pressure was high; and I had severe constipation for days into a week.

It was terrible for my husband, my family, and me! One day, my mother found a hospital that had just learned about the disease and Panhematin therapy. When I went in that day, I could not function. My blood pressure very high, and I had pain so severe I could hardly speak or move. I was not eating and had pain in my muscles and a headache. I was nervous and had constipation, but the staff worked so quickly and kept a close eye on me.

*The **Panhematin** came off the plane the next morning, and Dr. Anderson spoke with the physician treating me and advised him on how to care for me. I showed my doctor the APF website, and he went home and read through all the information related to AIP. He asked me questions and listened and believed me. And each day I went through my own checklist to make sure of the timing of my medications. I walked out of the hospital feeling so much better, and smiling. I was a new person. **Panhematin** works so well for me!*

I truly appreciate Lundbeck, Inc., the American Porphyria Foundation, and the doctors, nurses and pharmacists who have helped me. I also appreciate the support and patience of my family. Each person in a patient's life plays an important part in helping them. We need to spread the word about this rare disease and make it known in the medical field, so that all can be treated quickly and properly. In the end, effective treatment may mean saving the patient's life.

Star Award for Lundbeck

The APF is proud to announce our Corporate Star Award for Lundbeck, Inc., the company that makes and distributes Panhematin in the United States.

Lundbeck has been a standout for the APF as an underwriter of the **Protect the Future** program to train the next generation of porphyria experts. Lundbeck (formerly Ovation Pharmaceuticals) recognized the need for the **Protect the Future** program in 2002, when it acquired Panhematin. The need is clear and closely related to Lundbeck's commitment to keeping Panhematin available for acute porphyria patients in the U.S.

Because the acute porphyrias are so rare, few doctors are familiar with the treatment. For decades, heme therapy has been accepted unequivocally among porphyria experts as the standard of care in acute attacks, but of these experts, many have already retired, or will soon. Even patients who never meet a porphyria specialist face-to-face need their wisdom, and depend on their advice and support to our physicians when we are acutely ill. We thank Lundbeck, Inc. for helping to underwrite the **Protect the Future** program, keeping our future and our children's future safe.

Thank you for your ongoing support of the APF and its mission to promote the health of all people with porphyria.

AIP, Carbs and Me

Miranda Dennis grew up in an AIP family and was diagnosed with the disease herself a little over a year ago by DNA testing. She keeps the disease in check by being vigilant about her health and avoiding disease triggers like alcohol, fasting, and dangerous drugs.

Having AIP means I have to pay attention to my diet. Every time I am introduced to a new doctor they say, "You have porphyria? You do know you can't go on a crash diet, right?" I nod my head, aware that any type of fasting can trigger an attack. No holy moments under fig trees for me, no Biblical experiences fasting in the desert.



Doctors also make a point of reminding me to eat my carbohydrates. Again, I nod my head. When the world had gone Atkins-crazy with the high-protein, low-carb diets, I watched in horror as a TV chef made a sandwich with lettuce leaves instead of a bun.

I have been vigilant about keeping carbs respectfully in my life. But I don't find simply "eating carbs" to be helpful in actively protecting myself from heart disease, diabetes, and other diet-related health problems. So this past year I began incorporating more multigrains and whole wheats into my life. It's taken some getting used to, but now I love the earthy, sweet and nutty flavor of whole grain foods. I have never felt better, or healthier, and my eating habits have improved immensely.

I am no nutritionist, no scientist, no expert, but I can only think that what's good for non-porphyria people in terms of their carbohydrate consumption must be good for me, too!

RESEARCH IS THE KEY TO YOUR CURE!

In Memory

We are saddened to hear of the passing of our dear friends. Some of their loved ones have chosen to honor a life by making a gift to the APF. We sincerely appreciate their thoughtfulness and desire to help others with the disease. Please join us in thanking:

John and Lois Gragnola, Glenn H. Crocker, Robert and Mai Horn, Jon and Sandy Kautzman, Lillian Kehus, Deana K. Muto, Carol Mueller, FIS Harris Account, Thelma Rhoads, Theron and Linda Turner, Dan and Joyce Stranich, Lois Marshall, Don Schildgen, Bill and Pat Fiori, Marilyn Davis, Ann Arends, Melvin Jeter, Craig Jacklin, Sabrina Gray, Lyn Odenwald, John Kriha, Fred Clarke, Sandra Hill, Eileen Durand, Bill Cassano, Ken Stanczak, Thomas Tam, Souling Chong, Gary Horn for *Sandra Horn*

Thomas H. Aldrich, Dr. Jennifer P. Schmahl, Thomas Dechara, the friends of daughter Mary Simmons for *Anthony Puccia*
Emily K. Garner, Nancy L. Nelson, Louise H. Davis for *Denise Byrd*

Dr. William Morton for *Dr. Dave Downey*

Kathleen Toelkes for *Donna Pagano*

The Nagin Family for *Dustin Drapkin*

David and Lisa Barbour for *Lee Ann Kennedy*

Sophie Marshall for *Susan and Edward Marshall*

Dolores Brazas for *Wesley J. Brazas*

Yvette Strange for *Margaretha Morand*

In Honor

Others have honored a loved one with a donation:

Lynne Murray-Gray for *Ralph Gray*

Sharon I. Koch for *Matt and Wendi Koch*

Patricia J. Green for *Carissa Nunley*

Porphyria is an extremely painful illness, and can be life-threatening. The American Porphyria Foundation is working to improve the health of those who suffer with this rare disease by disseminating accurate medical information to patients, educating physicians in appropriate diagnostics and care for the porphyrias, and supporting advanced training for a new generation of porphyria experts. Your tax-deductible donation by check or credit card will help us continue our educational work and foster research efforts and the search for a cure. Thank you.

HealthWell Foundation Fund Panhematin and Acute Porphyrias



HEALTHWELL
FOUNDATION®

HealthWell Foundation has a fund to help those with acute porphyria cover the cost of Panhematin treatment. HealthWell can also help pay for insurance premiums and may be able to offer guidance in obtaining medical insurance.

Acute porphyria patients can begin the application process online at healthwellfoundation.org or by calling toll-free 1-800-675-8416.

Awareness Week, Continued from page 1 Educating About Porphyria Can Earn You an "A"



Phyllis Todd's daughter Rachel suffers from **hereditary coproporphyria (HCP)**, so Phyllis, who recently returned to college, decided to give a class presentation on the disease during Awareness Week. She came to the APF for help with materials, worked hard and read a lot about the disease. Despite some pre-speech jitters, the presentation went well, Phyllis even emailed once it was over letting us know her efforts paid off with a perfect grade. Congratulations Phyllis, nice work!

Women's Health & AIP

Karen Eubanks (AIP) was heading out of town just in time for Awareness Week when she found out about a women's health fair planned at the local hospital. She arranged with the organizers to get a table for porphyria information and did some education from afar.

Make Someone's Day Today

<http://www.makesomeonesdaytoday.com/>

Jessica Melton and her mother run a year-round fundraiser for the APF by donating a portion of each sale. Last week, Jessica wrote: "Each time I meet with a new client or future customer, we give them a little bit of info about porphyria and refer them to your website." The local Rotary club in Jessica's northern California town is helping to spread the word about porphyria too, and next month she will make a presentation about porphyria and her own history with **hereditary coproporphyria (HCP)** to a local business group.

Awareness Activities Still to Come

Since Awareness Week, we've heard from many more of you anxious to pitch in and plan something for next year. Awareness Week is a great time to act, but porphyria awareness can and should be a year-round thing. Remember, when you tell people about porphyria, you are helping other patients and yourself!

Here's what's on the horizon:

Bringing the Patient Experience to Brand New Doctors

Member **Jack Finnegan** writes from Pennsylvania: "the MD who originally diagnosed my **AIP** is now in charge of physician education at Akron General Hospital. Although we both have moved on, we've remained close friends. I am invited to give a patient experience talk to his new class of interns in June. I'll do it."

Reaching Health Workers and Community in Virginia

Member **Ellen Joyce** is speaking with the community health clinic, Women's Resource Center and churches in her Virginia town about doing a forum on acute porphyria. Ellen's family lost several women to **AIP** before rapid diagnosis and effective treatment were available for acute attacks. She wants to educate more people about porphyria and hopes to save other families from experiencing the same sorrow.

More Awareness Week stories on pages 2, 3, 4 and 6.



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

We Need to Hear from You! Please let us know if you have moved, if your home or work email address has changed, or if your home, work or mobile phone number has changed. Call us at 1-866-APF-3635 (273-3635) or email porphyrus@aol.com

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Website Quick Tip: The APF website is updated regularly. See the blue News boxes on our homepage for general or EPP News: www.porphyrifoundation.org

Thank You to Our New and Updated Members! You are an essential part of the APF and we couldn't do our work without you. *Thank you.*

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