



### **Celebrate! Happy 30<sup>th</sup> Birthday APF**



We want to add fun to the hardship of porphyria patients. To celebrate the APF's 30<sup>th</sup> Birthday, the APF is hosting a **Pet Beauty Contest**, which will begin the day you receive this newsletter and end May 15. Almost everyone, who has a pet, thinks theirs is the best looking and smartest pet in the world. We are giving you the chance to prove that and in the process, help fund our physician education publications for each type of porphyria. We send



very large, very comprehensive packets, which are well received by doctors nationwide. We have \$500 start, but we need \$10,000 to fund this project. With your help, we can educate ten thousand doctors. The contest works like this, you email or mail us a photo of your pet and a short bio, and we will post it on the **Pet Beauty Contest** on the APF website. There is a \$5.00 fee to enter the contest. Your pet will receive a bandana, and his or her photo and bio will appear on the website Pet Page on March 31, 2012.

Donations/votes can be cast in several ways. You can collect votes/donations from friends, families, and neighbors and send them to the APF or they can find your Pet's photo and click on it to cast their vote with their donation starting April 1, 2012. The votes will show with your pet's photo. Either way will work, but start right away because the contest ends May 15th. *There will be two winning categories: 1) The pet who receives the most funds and 2) The pet who receives the most number people to vote for it, thus giving everyone a chance to win.* The two winners will receive a trophy, a professional photo of you and your pet and a story of you and your pet in the next newsletter, the APF website, Enews, Twitter and Porphyria Blog. Who knows, with all of our promotion, your pet may receive national media attention. You will receive more information about the contest in the mail, but you can get a head start by sending in your pet's photo, and entering the contest now and viewing your pet on the website. *Don't forget, some animals have porphyria, too.*

As you can also see, we are celebrating our Birthday with a new Color Newsletter. How do you like it?



**Porphyria Research is the Key to Your Cure.** Unfortunately, the numbers of patient volunteers is very small. More volunteers are needed. Please contact the APF if you are interested in participating in one or more of the research projects below directed by these experts: Karl Anderson, University of Texas Medical Branch, Galveston, TX; Dr. Robert Desnick, Mount Sinai School of Medicine, NYC, NY; Dr. Joseph Bloomer, University of Alabama, Birmingham, AL; Dr. Montgomery Bissell; University of California, San Francisco, CA; Dr. Herbert Bonkovsky, Carolinas Healthcare Systems, Charlotte, NC; and John Phillips, Ph.D. University of Utah, Salt Lake City, UT.

- Mitoferrin-1 Expression in Patients with Erythropoietic Protoporphyrin (EPP)
- 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 Hereditary Coproporphyrin (HCP)
- Quantification of the Effects of Isoniazid Treatment on Erythrocyte and Plasma Protoporphyrin IX Concentration and Plasma Aminolevulinic Acid in Patients with Erythropoietic Protoporphyrin
- Hydroxychloroquine (HCQ) vs. Phlebotomy for Porphyria Cutanea Tarda
- EPP: Natural History, Genotype-Phenotype Correlations, and Psychosocial Impact
- A Pilot Study of Biomarkers Predicting Clinical Expression of Acute Porphyrias
- Transplantation in EPP: A Review
- Longitudinal Study of the Porphyrias



### **National PORPHYRIA REGISTRY**

Only **650** people joined the Porphyria Registry. With so few people registering, the government funding agencies will NOT provide funding for porphyria research. They monitor if there are enough patients to warrant research funding. Porphyria experts created the Registry for you to share information about your health and as a means to learn from the experiences of many patients around the country. They will then use the knowledge to enhance diagnosis, treatment and find a cure for porphyria. Please take five minutes and sign up for the Porphyria Registry. Then you will be contacted by one of the research team. Joining the Porphyria Registry is anonymous and free, and all data is stored in a secure, computerized database. No personal identifying information will be given to anyone without your expressed approval. PLEASE TELL FAMILY MEMBERS WITH OR WITHOUT SYMPTOMS THAT THEY ARE NEEDED, TOO. Click on the Porphyria Registry button on the top line of the Home Page of the APF website, click on *Join the Registry* and locate the Porphyria Research Consortium and follow directions.



**National Porphyria Awareness Week April 22-28, 2012** The challenge of living with porphyria starts with how little is known about it among friends, family and the medical community. That is why **National Porphyria Awareness Week** is so important. It provides each of **YOU** with the opportunity to enhance porphyria awareness among the public and medical professionals right where you live. Many of you helped last year, setting up at

hospital Health Fairs, seminars and grand rounds, gaining newspaper and television interviews, exhibiting at conventions. Some members even created their own campaigns to advance porphyria awareness, but we need more of you to:

**\*TELL** your story to local media. Television, newspapers, community magazines are looking for human interest stories about people who have encountered a major illness and have undertaken the challenge to help others in a similar situation. *LeAnn Cook facilitated a family interview in the local newsletter about the boys EPP struggles. The Fleegel family appeared in a documentary on EPP that aired recently.*

**\*SHARE** knowledge about porphyria at your doctor's offices and local hospitals. You might suggest that they host a seminar or grand rounds on porphyria. Some members have even set up an information table or exhibit at a health fair. *Amy Chapman sold Porphyria Awareness wristbands and set up seminars for doctors in her home town and even on vacation in Bermuda. Joanna Floyd attended Health Fairs and sent emails about porphyria to nearby hospitals. Nathan Carr provided educational material about porphyria to his hospital's medical library.*

**\*ASSIST** at an upcoming medical convention to help educate physicians on porphyria and/or ask your hospital or doctor if there is a local meeting where you can hand out materials. *Lana Spoto, Janie Williams, Molly Buffington, Craig Humphries, Jessica Melton and her Dad, manned the exhibit booths at the Association for the Study of Liver Disease and American Society of Hematology medical conventions.* You can do the same at this year's meetings.

**\*VOLUNTEER** your talents to help achieve the educational programs of the APF. Our talents are varied and plentiful and can be used to help one another. For example, you might want to donate one of your paintings, sculpture, weaving, etc. for our fall raffle. *An anonymous donor sent the APF one of his paintings.*

**\*VOLUNTEER** your skills, like computer expertise, business acumen, or other skills to help achieve the educational programs of the APF. Computer expert, *Rob Saupe, helped us with complex computer technical issues.*

**\*HOLD** a community race, car wash or other fund raising activity. *Clarita Kimball and Lauren Warren raced in "Night Runs" to enhance porphyria awareness. Wyatt King entered a Box Car race for porphyria.*

**\*HONOR** your loved one with a gift to the APF for a birthday, anniversary, holiday or memorial gift, like *Dr. Susan Engel did to honor Bill Kasper and Linda M Pisciotta to honor Dr. Rebecca Corley.* Here is one of the most unique ways: *Kate Ruby purchased 50 APF wrist bands to put in the favor baskets for each guest at her wedding to honor her aunt. More about the bride and groom and her aunt with porphyria story in the June newsletter .*

**\*WRITE** a letter to your friends and family asking them to make a donation like, *Ralph Gray* or vote for your pet in the **Pet Beauty Contest**, which will advance Physician Education and add some fun to our lives.

The APF can help you accomplish this goal by providing materials for your project:

Porphyria Brochures  
A *Porphyria Live* DVD  
Fact sheets  
A Powerpoint Presentation

Information for Grand Rounds  
Ideas to set up Medical Seminars  
Ideas to exhibit at a Health Fair  
Information to gain press

Press Releases  
Ideas to gain media attention  
Porphyria Testing Info  
And Much More



### **A Simple Gesture, Big Results**

Long time APF member, Ralph Gray, is a widely known Texas artist. Every year at Christmas, Ralph Gray helps enhance Physician Education funds. Because of his illness, Ralph is limited on the type of his activities he can do for the APF, so each year simply mentions to all who are on his special card list that they might donate to the APF as part of their end of the year giving. Sometimes he includes patient stories to illustrate what a patient endures. His is just a simple invitation for others to help. From Ralph's annual gesture, his friends and family donated generously to enhance Physician Education. You, too, can advance physician education with a similar effort. Some members donate in honor or memory of

friends or family, while others choose other creative means to further this most important goal.

Amy Chapman promoted and sold the wristbands on the APF FACEBOOK group and Rob Saupe did a 100 mile walk and used the APF internet Firstgiving website to more easily allow people to donate and create their own campaign.

Weenzie, Dick Howe's dog, sometimes wears his APF bandana to show he is a supported porphyria awareness. You, too, can purchase an APF bandana for yourself or your pet for \$5.50 by contacting the APF and giving us your pet's collar size or sign up for the Pet Beauty Contest and get one free. You can choose any means to help. Regardless of the means, it is the end that is vital.

## ***It's not about finishing. It's about starting***



The Las Vegas Review-Journal News reported recently, "Of all the stories that have come out of the Rock 'n' Roll Las Vegas Marathon and Half-Marathon Night Run, the one about the

"Race Ninja" has to be one of the coolest." The "Race Ninja" is our own APF member, Clarita Kendall, who participated in their run covered from head to toe to protect herself from the light. After the race, she received a great deal of publicity for herself and porphyria. Clarita joined the race because she has EPP and racing in the daytime is brutal, *"When exposed to sunlight, I experience excruciating, burning pain. My skin turns red and peels. I become weak, fatigued and have difficulty breathing. I have horrible reactions and get really sick."*

Clarita has to train in the wee hours of the morning, before sunrise because of her severe photosensitivity. She runs then or starts running after sunset near home close to the university. Her "unofficial crew" is the campus police, who grew to appreciate her late-night runs around the university campus. Just like most runners, Kendall has found that running, even at night, improves her mental and physical health.

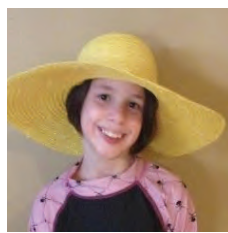
Clarita says it is more physically challenging for her to drive ten miles in the daylight than to run ten miles in the darkness. The only problem once she found out she enjoyed running was finding night-time races, so she could feel "just like everybody else." For the first time, people were meeting me as an athlete and not as a disabled person.

*"I can be part of the world again for a while," she said. "I have parameters, and I want to fill these parameters to the very edges. It doesn't matter how I finish. It's not about finishing, it's about starting."*

Clarita has both a severe case of EPP and Lupus, so finding people who understand her situation is not easy. So Clarita is looking for other endurance athletes or persons with interest for her new Night Runner Facebook page. She says, *"The page is for ALL people who are sensitive to light. If people are interested in running, or walking and aren't sure how to get started or find a group of people with similar challenges, I hope that they'll check out this page."*

If you are interested in joining a NIGHT FUN RUN, please contact the APF. We will be sponsoring a night run this summer. Lace up those running shoes.

<https://www.facebook.com/groups/285918944785966/>



## ***Megan's Surprise***

If you want to laugh and cry at the same time, read her wonderful story and view the *You Tube* about 8 year old, APF member, Megan Dawson. Megan, who has EPP, is the youngest volunteer ever to serve at the APF medical convention exhibit booth. She is so small in the photo, you can barely see her at the booth but she did an incredible job passing out porphyria information to physicians and helping them understand EPP.



Recently, she received a BIG surprise from her mother, Mandie's, MBA college classmates. In the course of conversation with a friend, Mandie mentioned that Megan liked Halloween because it was fun in the dark. She explained Megan's photosensitivity and expressed how hard it was on Megan not to be able to play outside when the sun was shining. Unbeknownst to Mandie, her friend shared Megan's story with their classmates, noting that Megan's wish was to be able to play in the daytime like other kids. The classmates secretly purchased a large playground set and other friends decided to join in the effort and purchase a UV protective canopy and mulch and landscaped the area. Mandie filmed Megan's big surprise and the friends watched the joyous moment.

See YouTube:

<http://www.youtube.com/watch?v=WFct-Kp5KxI>  
or Type in Mandie Dawson in the You Tube site.

***Thanks Andrew*** APF member, Andrew Crask, gave us a wonderful surprise recently. He called the office to thank us for changing his life. A few years ago, Andrew contacted the APF about his illness. After speaking with him, we suggested he get tested for Porphyria Cutanea Tarda (PCT) and shortly thereafter, he received a positive PCT diagnosis. Andrew's doctor did not know about porphyria and was happy to receive the APF information. After following the treatment regime carefully, Andrew improved and has remained well.

Andrew is a decorated Marine Corps veteran, who is a passionate patriot involved in veteran's issues and is also an inventor with amazing patents. Despite losing his sight and having PCT, Andrew lives joyously and wants to share it with others. When we asked him his secret to his good life, he said,

***"Tell people to love each other, love God, eat right, go to church, see your doctor and read the information from the APF to stay well."***

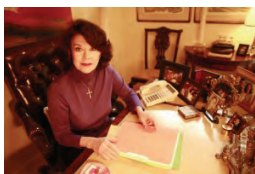


**New Board Member, Warren Hudson** is a long-time supporter of the APF and now our newest board member. Warren hails from Austin, Texas where he graduated with a Masters in Business Administration from the University of Texas. Warren is shy to tell that he also played football at UT, quite an achievement in a football loving state as Texas. At present, Warren is a Director with Hudson & Meyer CPA, LLP., which is based in Dallas, Texas. He and his wife, Rose, have been involved with the APF for a decade and are always willing to help with special projects.



When Rose first began having symptoms, she and Warren went on a quest together to find a diagnosis. Like so many people, their search was not easy. Through what Warren calls, "dumb luck," they called a number they saw in the phone book. To their astonishment, the receptionist had heard of porphyria, because the new doctor they called had studied under porphyria expert, Dr. James Kushner, at the University of Utah School of Medicine. Rose was diagnosed with AIP, and shortly thereafter participated in her first research project with Dr. Karl Anderson. Prior to being on the study, Rose had several severe attacks. Fortunately, after being diagnosed and being in the study, she did not have an attack for a year. But, the cycle of attacks began again, so Rose spent many visits in the hospital with serious attacks. Warren slept on the floor beside her and provided guidance to the doctors.

Warren says that having empathy is key as a caretaker, as is learning everything possible about porphyria. We are grateful that Warren will join us as a new Director.



**Lyon's Share** Thirty years ! I can't believe it was over thirty years ago that James Young and I met for the first time to discuss the need for a porphyria support

and educational organization. We were the two members and our unpaid employees were my 11 year old daughter, Lelia, and my 13 year old sister, Elizabeth. We did have the most prestigious Scientific Advisory Board (SAB) of experts of any rare disease group in existence and still do. This group of doctors/scientists gave us extraordinary credibility from day one!!

So, with no experience and only money from our own pockets, we set out to create an outstanding foundation that would meet a very serious need--the lack of information about the porphyrias. Until the APF, patients had no educational materials and physicians had medical text books filled with biochemical and not clinical information. Now copious information and misinforma-

tion is at our fingertips. Fortunately, the SAB separates correct from incorrect data, thus providing a PLACE TO GO for reliable information and guidance via the APF. Celebrate with us in the upcoming year by participating in the National Porphyria Awareness Week, April 22-28, 2012 and the APF 30th birthday. Since the APF is YOU, you will receive information soon on how to participate.

Unfortunately, the **340 B Hospital Budget Expansion Bill HR 2674** is before Congress again. If this bill passes, rare disease drugs, like Panhematin, will be in jeopardy. To explain, this bill would require certain drugs to be sold for much less than it cost to produce them. As you can easily see, the manufacturer under these conditions could no longer afford to produce the drug. If you are taking Panhematin or want to help those who do, please contact your legislators and ask them to vote "NO" on the bill.

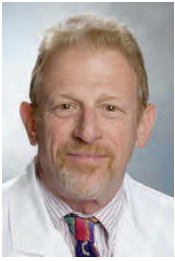
### ***EPP Has Made Me A Better Person***

I am Elyse Adams. I am a 25 year old mom of two and I have EPP. After three years of symptoms, accusations and many doctor's visits, a wonderful dermatologist, Dr. Jorge Crespo, diagnosed me with EPP at the age of five. I am the only person in my family with EPP symptoms but I do have a great-grandfather who was very sensitive to the sun. Fortunately, my children do not have symptoms. I am grateful that they do not have to suffer, because coping with this disease can be difficult, especially the pain.

It is emotionally and physically painful. In Junior High, I went to cheerleading camp in July. My parents bought me a suit that was supposed to protect me from the sun, but it didn't work, so I had to leave after one day. The girls laughed at me, which only made matters worse. It was the first time I thought I might actually die from pain. My brother was very sweet and nailed blankets to all of the windows in our house and made sure the dogs did not jump on me. He was only ten at the time.

Now, I have learned that I can be in the sun for ten minutes before the "tingles" begin. After the tingles start, I must go inside, or I will suffer. When I am in the sun too long, I have to sit in air conditioning in complete darkness. I dread the spring/summer, but I love winter and fall because I do not have reactions in these months. I am the person I am today because of the EPP experience has made me a better person. Editor's note:

*Read the rest of her wonderful story on the APF website under **Member Stories**.*



**Safe/Unsafe Drugs** Dr. Peter V. Tishler, who is a porphyria expert at Harvard/ Brigham and Women's Hospital in Boston, has been instrumental in overseeing and updating the APF Safe/Unsafe Drug List for acute porphyria. Dr. Tishler is kindly updating the list again and wants your input. Therefore, if you have been negatively affected by a specific drug, please contact the APF. We will then put you directly in contact with Dr. Tishler to discuss your experience. When you report a drug, please have on hand, the name of the drug, the dose, and a synopsis of what happened to you when you took the drug. As you know, the Safe/Unsafe Drug List is extremely important for people with acute porphyrias, so your input is very important. It is often a lifesaving tool for the patients and their doctors.

Dr. Tishler is a clinician/researcher in human genetics, including polycystic kidney disease, chronic obstructive pulmonary disease, Fabry's disease, and the porphyrias. We are fortunate to have porphyria specialists, like Dr. Tishler, to devote himself not only to our present health needs but to help assure a healthier future for each of us. If you have any questions, please contact the APF immediately.

**Longitudinal Study Underway** The Porphyria Longitudinal Observational Research Project is underway. The objective of this protocol is to conduct a five year, multidisciplinary investigation of the natural history, morbidity, and mortality in people with porphyrias. In addition, the purpose is a long-term follow-up study of a large group of patients with the various porphyrias, which will provide a better understanding of the natural history of these disorders, as affected by available therapies, and to aid in developing new forms of treatment. You have the opportunity to be part of this important project and help advance research by answering the most important and often perplexing questions about porphyria. As part of the research,



the patient volunteers will be followed longitudinally for long term survival, development of disease complications and outcomes of commonly used treatments, as well as more advanced treatments, such as liver or bone marrow transplantation. Researchers will seek to identify biochemical features (biomarkers) that may predict future symptomatic episodes so that interventions can be initiated before symptoms develop. The patients enrolled in this study will also be a source for other studies, including mechanistic investigations and clinical trials.

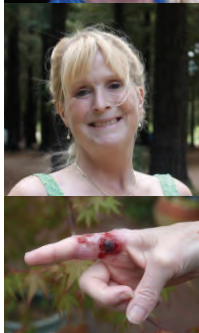
The questions researchers want answered include:

- a.) *In a longitudinal cohort, what is the prevalence of specific morbid indicators of disease severity, including neurovisceral and cutaneous manifestations, levels of porphyrin precursors and porphyrins, quality of life, long term effects on the liver, kidneys and other tissues, and case-fatality associated with the various forms of porphyria?*
- b.) *What are the relationships between disease severity and progression and various biomarkers-biological characteristics, such as genotypes, causative and contributing endogenous and environmental factors and levels of porphyrin precursors and porphyrins?*
- c.) *What is the safety and efficacy of currently used and new therapies for the porphyrias, especially in the long term?*

**Porphyria Cutanea Tarda** With the acute porphyrias, the patients often complain that doctors can't see what is wrong with them as ain does not show on the outside. But with PCT, the bad blisters make it easy to tell something is wrong. When a doctor is educated, he or she can tell PCT immediately and know the tests for it. Urinary porphyrin levels are abnormally high in porphyria cutanea tarda patients (PCT,) with several hundred to several thousand micrograms excreted in a 24-hour period. The excess porphyrin pigment is often grossly evident in visible light and yields a pink fluorescence under Wood lamp (black light) radiation as shown above.



APF member, Vivian Evans, suffered for years before a chance doctor finally discovered she had PTC. She contacted the APF and received information about diagnosis and treatment, after which she finally got her severe blisters under control. Vivian could not tolerate phlebotomies, so her doctors used another treatment, which proved successful.



Recently, Vivian joined the Porphyria Registry on the website and is already entered in to the Porphyria Research with Dr. Montgomery Bissell and his team. Vivian kindly sent us her photos to use to teach about PCT. The first photo is of Vivian when blisters appeared in full force on her face, hands, and sun exposed areas of the skin. The next was taken at a wedding where she was blister free and able to tolerate the sun. The third photo is of her hands. Those blisters were bloody, pus filled and bleeding for six months. Although she is better now, she and her doctor monitor her PCT to stay well. PCT can cause serious liver damage. If you have PCT be careful to avoid the aggravating factors, like iron, alcohol, Hepatitis C Virus (HCV), HIV, estrogens (used, for example, in oral contraceptives and prostate cancer treatment) and possibly smoking. You can join the Registry on the APF website homepage and don't forget to enter your pet in the contest.

## My 100 mile Hike for Physician Education



My name is Rob Saupe and I have EPP. As you can see from my photo, I have to wear sun protective apparel, because the EPP has made me very photosensitive. I wanted to help fund the APF Physician Education program so I chose to complete a **100 Mile Hike** and accomplish three things in the process. First, I wanted to raise funds to help educate doctors how to give proper treatment and care to those of us living with Porphyria. All the physician information is written by Porphyria Specialists, so we know it is correct. Next, I wanted to raise community awareness. I hiked on a local trail that is used by many locals and tourists. Seeing me dressed in my protective gear raised many eyebrows and a lot of curiosity. After seeing me on the trail for many days, they started to ask me questions. This opened the door for many great discussions about EPP. Sharing on Facebook helped spread the awareness amongst my friends and others. I also wanted to give back to the APF. The APF has been the reason that I have had such great medical care for the last 30 years. Desiree, the APF Staff and the porphyria specialists have devoted themselves to improving the care that Porphyria Patients receive.

The hike was a great experience, and it helped get me in better shape! Having Porphyria doesn't have to dictate our lives. We just have to make adjustments to how we live it, and do the best we can. Live, Love, and Enjoy!

Editor's note: Let me brag on Rob for a moment. Rob was a volunteer for the EPP clinical trials with SCE-NESSE/afamelanotide, participated in an ABC story about EPP, is an administrator for our APF FACEBOOK group, assists the APF with computer technical issues and has been a valuable asset to the APF. Thank you, Rob.

**Physician Education Goal:** We need \$20,000 to update and publish Physician Brochures, which will elaborate on the diagnosis and treatment of porphyria and relate ongoing research efforts of each of the porphyrias. We also want to reach 15,000 more physicians, as well as each of your doctors. As you can see from the table below, we have a beginning donation of \$500, a long way from our \$20,000 goal. But if we contribute or enter our pets in the **Pet Beauty Contest** and have friends and neighbors vote, we will reach the goal.

<b>PET BEAUTY CONTEST goal is to publish and distribute Physician Brochures, AIP, VP, HCP, EPP, CEP, PCT, HEP, and ALAD. Watch the donations grow and meet our goal.</b>	
<b>\$ 500</b>	<b>\$10,000</b>



**Patient/Physician Relationships** The APF believes that when the patients and doctors establish a solid rapport, patients will have a positive impact on the quality of care they receive and, in turn, better access to treatment. The APF also hopes to enrich our member's doctor/patient relationship by inviting the patient's perspective: we want to gather and publish examples from YOU on how YOU were able to build a good relationship with YOUR doctor.

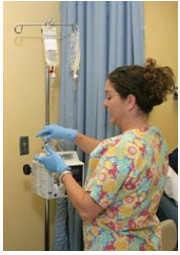
Also, the APF will be publishing the doctor' list of *Patient's Rights* on the APF website. This is a means to help YOU understand your right to know your treatment options and take part in decisions about your care. YOU have the right to ask about the pros and cons of any treatment, including no treatment at all. As long as you are able to make sound decisions, you have the right to refuse any test or treatment, even if it means you might have a bad health outcome as a result. You can also legally choose who can speak for you if you cannot make your own decisions. You have a right to considerate, respectful care from your doctors, health plan representatives, and other health care providers that do not discriminate against you based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment. Your comments and suggestions will become part of a new section on the APF website: Physician/Patient Relationships and Patient Rights. Please send your comments about how to create a good relationship with your doctor or how the Patient's Rights can help you to: **porphyrus@aol.com**.



If you have had an email or mailing address change, please let us know at the APF office. If we don't have your present contact information, your newsletters, ENEWS and special mailings will be returned to the APF office and we will have no way to contact you. We also suggest you send us your cell or home number for special purposes, like media opportunities, research updates, and other educational materials. We have even had long lost relatives reach out to family members via the APF. Part of keeping updated is

keeping the APF updated with your present contact information.





**Panhematin as a Preventive Measure** Read how Panhematin® changed Betsy's life. *Even after I was diagnosed for a few years, I still had bad attacks every month, sometimes twice a month. Usually, I was in the hospital two or three times a month for four or five days, or I was in the hospital once a month for a long time. I had so many attacks that it seemed I never had a time I was not in an attack. It took a while to realize that my attacks went along with my menses and ovulation. My doctor put me on Lupron to stop the cycle. I tried it for about six months, but I couldn't tolerate it. Other women use it and do well. So when I read in one of the APF letters some people take Panhematin once a month to prevent attacks and some women take Panhematin at their menstrual cycle to prevent an attack, I asked my doctor if he thought this regimen might work for me. He said it was worth a try and started me on Panhematin before my next menses. We expected it to take months before my attacks would slow down, but by the second month, I was already better and didn't have an attack.*

*My doctor set up a Panhematin prescription and made arrangements for me to get the infusions easily. I don't have to wait until the nurses contact his office and go through a lot of paperwork. The hospital has the Panhematin on hand and the pharmacy gets it ready as soon as I walk into the clinic. My attacks have stopped almost entirely unless I have the flu or some bad infection. Thank you APF for the information. Preventing attacks GAVE ME A NEW LIFE. Betsy L.*

### **Rare Disease Day**



This year, rare disease was the focus of a rare day, February 29, 2012. It marked the fifth international Rare Disease Day organized with rare disease national alliances in 25 European countries under the banner of EURODIS, a coalition of rare

disease organizations. Now celebrated in the USA, on this day hundreds of patient organizations from over 40 countries worldwide organized awareness-raising activities converging around the slogan "Rare but strong together." The APF has been involved with Rare Disease Day each year with special activities planned to advance awareness of rare diseases.

### **Renew Your Membership**



If YOU have not renewed your membership in the APF, please do so. It is easy to think that someone else can keep the APF at work but it takes all of us.

- Answering patient and doctors' calls,
- Updating & maintaining the website, publishing educational materials,
- Educating doctors & patients,
- Contacting the media,
- Locating government grants for research,
- Facilitating support networks,
- Funding training of future experts,
- And so many other services.

We cannot maintain and facilitate the many educational and support services without your donations. It takes us all to make the APF thrive and grow. Please make a donation and send it in the enclosed envelope.

### **In Honor and In Memory**

**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:*

Melissa Breaux for **Nancy Ford Drury**, Ralph M Gray for **Fred Little Gray**, Gary and Elise Grabner, Stephen Schlickman, Kathleen Toelkes, Evelyn M Shellgren, Carol Lambert, Ila Roberts, Jean Clinger, Andria Polk for **Anthony V Pagano**; Mary Puccia Crown for **Dean Puccia**; Joe L Yager for **Arlene J Yager**; Norma Brown for **Matthew Brown**; Sophie Marshall for **Susan Marshall**; Donald L Johnson for **Peggy Lewis Johnson**; Paul Busse for **Vivienne R Busse**; Frank L Feczko for **Robert Zieles**; Vickie Gehm for **Judy Coley**, Susan and Robert Laskin and Family and Joan and Jeff Karelis for **Bonnie Marcus**.

★ **In Honor** *The following members have chosen to honor their friends with a gift to the APF. We sincerely thank them for their kindness.* Eric S Gray, Mary Frances Donnelly, Kathleen Angela Shiel, Lynne M Murray-Gray, Richard and Ratchel Marroquin, Ruth Wilson, Grayfred Gray, JoLynn Foldesi, Larry and Sarah Pritchard for **Ralph M Gray**; Lisa Neal for **Raymond Neal**; Etta L Insley for **Desiree Lyon Howe**; Rita Rhoades for **Lisa Rhoades**; Linda Sue, Joanne and Kim Stadtmiller for **Pati Hoover**; Anne L Johnson for **Candace Johnson**; Les Holladay for **Joel Holladay**; Dr. Susan Engel for **Bill Kasper**; Linda M Pisciotta for **Dr. Rebecca Corley**; Diane and David Russell for **Nicole and Craig Leppert**; Mary Puccia for **Mary Blanch Hargett**.



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.

All information and content on this Web site are protected by copyright. All rights are reserved. Users are prohibited from modifying, copying, distributing, transmitting, displaying, publishing, selling, licensing, creating derivative works, or using any information available on or through the site for commercial or public purposes.

## *What's New at the APF*

[www.porphyrifoundation.com](http://www.porphyrifoundation.com)

**Tell Your Doctors About the National Registry. It is very important. Your doctors may have other patients who need to know about the APF and the Registry.**

**Tell your doctor about the Safe/Unsafe Drug Database for Acute Porphyria and Emergency Room Guidelines for Acute Porphyrias. All APF medical information is written by porphyria specialists.**

**Is Your Membership Up to Date? Don't miss a newsletter! Please take a moment to renew at our website, or call us at the office: 713-266-9617 or 866-APF-3635. Thank you.**

**Contact the APF If Your Doctor Needs a Dr. Packet. We will send a comprehensive packet to your doctor free of charge. Just call the APF with your doctor's name and address and your type of porphyria.**

Non-Profit  
U.S. Postage  
PAID  
Carol Stream, Illinois  
Permit No. 1

Address service requested

AMERICAN PORPHYRIA FOUNDATION  
280 Maple Drive, Bloomington, IL 61708

