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.porphyriafoundation.com

Updated Member Stories Section: Find full-length versions of the member stories in this issue of the newsletter, and several more new ones.

Be sure your doctor knows about the Drug Safety Database for Acute Porphyria at www.apfdrugdatabase.com/ and remember to join the National Registry so you can be counted!!!

Is Your Membership Up to Date? Stay current on all the latest news about testing, treatment, and member meetings in your area! Please take a moment to renew at our website, or call us at the office: 1.713.266.9617 or 1.866-APF.3635.

The Emergency Room Kits have been updated and expanded. This is the best money you have ever spent. Also an APF DV porphyria live and get one free for your doctor.

How You Can Help
TELL your story to local media. Television, newspapers, community magazines are looking for human interest stories about people in their community who have encountered a major illness and undertaken the challenge to help others in a similar situation. Remember Cason and Caul, sons of Lee Ann and Chris Cook, whose EPP story warranted a full page in their local newspaper.

SHARE knowledge about porphyria at your doctor’s office 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. Give your doctors a DVD or tell them about the free CME courses on the acute porphyrias for their continuing medical education. Think of Amy Chapman who has been sharing her porphyria story to various doctors groups in her city and others states.

VOLUNTEER your talents and skills, like computer expertise, business acumen or other skills to help achieve the educational programs of the APF. Your talents are varied and plentiful and can be used to help one another. For example, you might donate one of your paintings, sculpture, weaving, etc. to doctors groups in your city and others states.

HOLD a community race, car wash or other fund raising activity to support research or an APF program of your choice, Physician Education, Patient Education, Protect the Future program to train the next generation of experts. Remember Parker Snyder, our youngest fundraiser, who distributed porphyria information at his wrestling match or our Ironman, James True, who raced for porphyria.

ENCOURAGE your doctor to present a seminar on porphyria using the Power Point Presentation on the website. Many APF members have told their doctors about the free Continuing Education Course (CME) and they have taken it.

Porphyria Awareness Week April 16-23, 2011
The challenge of living with a rare disease starts with how little is known about it—among friends and family and in the medical community. Raising porphyria awareness is about improving the quality of your life through greater understanding, increasing the chances of prompt diagnosis and improving your access to the right medical care. National Porphyria Awareness Week provides YOU with the opportunity to help the public and medical professionals in your community more readily recognize the need for better diagnosis and treatment of porphyria. Since many of YOU have asked for suggestions to accomplish this important mission, we have provided the following list. We also have many materials to assist YOU in this important mission; Fact sheets, Posters, Brochures, Overviews, DVD’s etc.

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The APF has a very active media campaign for television, film and print media to promote porphyria, and we have enjoyed amazing results. The most important end result is that patients across the country were diagnosed with the disease and are being treated.

The following is a list of programs which also have featured porphyria or a patient with porphyria:

- HOUSE, Honeymoon, Season 1: episode 22
- HOUSE, Fools for Love, Season 3: episode 5
- HOUSE, Finding Judas, Season 3: episode 9
- HOUSE, Don’t ever Change, Season 4: episode 12
- HOUSE, Guardian Angels, Season 4: episode 4
- HOUSE, Whatever it takes, Season 4: episode 6
- HOUSE, Itch, Season 5: episode 7
- HOUSE, Emancipation, Season 5: episode 8
- HOUSE, Let them eat cake, Season 5: Episode 10
- GRAY’S ANATOMY, Time Warp, Season 6: episode 15
- HOUSE, Vampire Weekend, Season 2, Episode 6
- SCRUBS, My Orlando Infection, Season 4, Episode 13
- SCRUBS, Kelso’s last stand, Season 9, episode 9
- SCRUBS, My Dumb Luck, Season 9, episode 7
- SCRUBS, Cutie here like Vladimir, Season 8, Episode 4
- CSI: Miami, Justice Served, Season 1 Episode 21
- CSI: Los Angeles, Once Bitten, Twice Damned Season 2
- ABC News Specials, Medical Mysteries Series, episode 2
- ABC News, Desiree Lyon interview
- ABC News, Vampire, A Medical Myth Nov 2009
- FOX News, King George, Madness or Arsenic July 2005
- BBC News, Desiree Lyon
- Sanjay Gupta, CEP patient, Kasey Knaf CEP
- Anderson Cooper 360, CEP
- CNN, documentary on CEP patient, Kasey Knaf
- CNN, interview Desiree Lyon (CNN HERO)
- Dr. Oz, EPP patient, Craig Lappert
- National Geographic, Feb 2010 Six Ways to Stop A Vampire
- Court TV

My name is Allie Campbell and I am a patient with porphyria. I helped on the back of my hands and on the end of my toes. The pain was so fierce I could not even wear shoes. On a hot day, I would feel like my skin was on fire and itched so much that it felt like it was unzipped. By then, I had been to 11 doctors and decided to try a dermatologist. He took one look at me and said I had a rare genetic disease called Porphyria and promptly sent me to the University of Southern California which at that time studied Porphyria. I learned how to avoid these attacks by eliminating alcohol and using very smart judgment about the sun during the eight hottest months of the year, wearing sun protective clothing, and playing golf very early in the morning.

I began to study nutrition to save my own life, however, it was through the American Porphyria Foundation that I received the most education to understand this disease. For a person with porphyria, the quality of one’s life is being able understand what is going on and to be able to avoid attacks. Right now, I am living my American Dream of feeling as GREAT as possible every day and enjoying the fullest. It is definitely a full time job being diligent to avoid Porphyria attacks, gain knowledge, and live a normal life because I deserve it, and so do my husband, family and friends.

Remember the Alamo

If you remember our turtle friend, Alamo, then you have been a longtime member of the APF, because he was 23 years old on March 9, 2011. Alamo has been a member of the APF since she was a baby and was the only non-human member of the APF for twenty years. It wasn’t until Alamo lay eggs that her parents, Claire and Robert Sadowsczak of Orlando, Florida discovered he was a sea turtle.

The APF wants to wish Alamo a very Happy 23rd Birthday.
We are proud to welcome Dr. Maged Kadry Rizk into our PTF program. His first PTF training experience will be the International Porphyria Conference in Cardiff. Dr. Rizk, who practices at the Cleveland Clinic, in Cleveland, Ohio, earned his Bachelor’s of Science and Medical Degree at Lourenco, will be attending, as will a number of our other Protect the Future doctors. This is an exciting opportunity for them to meet their international counterparts and a challenging educational experience to enhance their porphyria expertise.

Dr. Rizk is a key participant in an upcoming Emergency Room Interactive, which will assist ER physicians to recognize an attack of acute porphyria and educate them on how to best treat patients who are in an attack. Dr. Rizk is quite knowledgeable about porphyria and is seeking to broaden his expertise in the field. He is looking forward to training with the best experts in the country and will begin with the conference in Cardiff. Dr. Rizk will then join Dr. Karl Anderson for a special Porphyria at the University of Iowa Hospitals and Clinics and a Resident in Internal Medicine at the University of Illinois Hospital-Chicago. Dr. Rizk has a distinguished list of awards and publications, as well as a mission award for his work in south Africa, Zimbabwe, Zambia.

The Canadian Porphyria Foundation is supporting the travel so that Protect the Future doctors as part of their training. They are joining their US colleagues to meet other experts around the world. Our Brazilian trainees, Dr. Guismer Perini, and Dr. Charles Lourenco, will be attending, as well as a number of our other Protect the Future doctors. This is an exciting opportunity for them to meet their international counterparts and a challenging educational experience to enhance their porphyria expertise.

We are so fortunate that one of members has made a $100,000 matching grant, which has been matched!!! However, this training is very costly so we need your help to train Drs. Balwani, Liu, Singal, Mittal, Lee, Lourenco, Wickliffe, Perini, Naranj, Thapar, Sood, Freilich, Parker, Guy, Wang, and our latest Dr. Rizk.

To donate to this program, please mark your donation - PTF. Thank You!!

We are the Much More

APF member, Susie O’Berski, has written a warm, wonderful, challenging and encouraging book, We are the Much More. She includes an episode about her bouts with Hereditary Coproporphyria (HCP), relating how she was diagnosed and treated.

We are the Much More is a book on faith and the joy that her faith has brought her and her family. Susie shares her faith, family, friends and fun in her story.

If you have written a book or article, please share news of your creation with the APF. Our members enjoy hearing about and reading the work of other people with porphyria.

We would love to see your paintings, photographs, gardening or any other handwork. We are a creative group. Many thanks.

In Memory

When our friends pass, we are very saddened because many of them have become dear friends. Some of their loved ones have chosen to honor their life by making a gift to the APF. Please join us in thanking:

Helen and Donald Herman, Barbara and Dwight Meyers, Karen S. Hall, Kathleen and John Howell, Nancy L. Graha-Myers for Laurie E. Breier, Donna and Richard Coffey, Susan and James Evans, Joan and Robin Brown, C. Gayle Mitchell, Myrna Levy for Dorothy Simko, Kathleen and Robert Clasing, Village of Hortonville, Bill Ferminich, Patricia A. Ratzlaff, Paul D. Baumgart, Mike Huzzar, Blankenheim Services, Debbie and William Ferminich, Trisha J. Gavin, Carolie and Daniel Laird, Laura Newhouse, Auren and Stephen Rader, Saralee for Hildegard Ferminich, Nita Busby for William Frederick Petrunia, Elaine and Thomas Smucznyski, Smucznyski Family, Darby and Paul Busse for Vivienne R. Busse, Joe L. Yager Arlene J. Yager, Gary R. Horn for Sandra Horn, Dolores M. Brazas for Wesley J. Brazas, Dr. Susan I. Engel for Lee Engle, James E. Arzouman for Susan M. Arzouman, Rene Madeux for Kathleen Madeux, Grace Ann Fecsko for Robert E. Fecsko, the many friends and husband of long time member, Dorothy Shell, Dorothy helped a host of people with her book and her love.

In Honor

The American Porphyria Foundation is working to improve the health of those who suffer with this rare disease through outstanding physician and patient educational programs. We thank those people who honored their loved ones with a donation to the APF.

When I had surgery when I was 21, I didn’t improve. Instead, I spent the entire summer in pain, throwing up, no feeling in my hands and feet, and blisters on my arms. Although the doctors ran many tests, they could not come up with an answer. Finally, in desperation, our family doctor sent me to Mayo Clinic. After more weeks of intensive tests, a doctor came in with a grave look and said, “You have Acute Intermittent Porphyria.” He didn’t look very happy, but I had the weight of the world lifted from my shoulders, because I finally had a name for what plagued me. That diagnosis was my present for my 22nd birthday. I had been given a barbiturate, which is an unsafe drug. I also had developed staph infection and been given sulfa, another unsafe drug, all of which had made me very ill.

The doctor went on to say, “We have no cure. We don’t know much about the disease. All we can do is try to keep you comfortable.” That was 35 years ago. I have spent a lot of time in hospitals and nursing facilities, but through it all, I have learned a lot and met many interesting people. I have been a participant in five research projects so hopefully my struggles have helped someone. When I was first diagnosed I was so frightened. My mother and I spent hours in the college libraries reading about porphyria. People living with rare diseases should be entitled to the same access and quality of care as any other patients. But today the reality is far from that. The rarity of patients, medical experts, knowledge and resources are aggravating the vulnerability of rare disease patients who are suffering from life threatening, debilitating, and chronic diseases. We are certainly not asking for more or better access and care than for other chronic diseases. To the contrary, we share the common cause of all chronic diseases. However, we believe that rare diseases is one of the most dramatic cases of health inequalities today both internationally and in particular in Europe. Therefore, the APF participated in activities nationally and joined a host of other countries around the world promote Rare Disease Day. For example, Stephanie Simpko manned a Living with Rare Disease Day table at her local hospital.

**Terri Witter** has been a member of the APF for a long time. Her story reflects many years. Her story, which follows, is similar to that of many of you.

The American Porphyria Foundation has been my support group, my fountain of knowledge, my rock! They are the “Jerry Lewis” of Porphyria— raising money for research, supplying educational pamphlets and Emergency Room booklets, and a website for doctors and patients, organizing get-togethers to help us find each other. In short, a God Send and Answer to Prayer. Thank you, Terri.

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**Testing Chart**

Members have requested that we reproduce the following chart to help them understand the tests used to determine if an acute porphyria could be their diagnosis. Notice the importance of the PBG test. When acute porphyria is suspected, confirmation should be initiated immediately by biochemical or DNA testing. Measuring urinary PBG is most important for diagnosis of acute porphyrias. Porphobilinogen (PBG) excretion is normally 0-4 mg/day and is approximately in the same range when expressed as mg/g creatinine or even as mg/L. In an acute attack, spot urine (PBG) levels are substantially increased (20-200 mg/L).

The test should be established at the local hospital pathology chemical laboratory. It is recommended that all medical centers provide for rapid testing for increased (PBG), since sending samples out to a referral laboratory can greatly delay diagnosis and treatment. Thereby, when acute porphyria is suspected the diagnosis can be ruled in or out in a timely fashion. The experts recommend rapid detection of increased urine porphobilinogen (PBG) using the Rapid PBG test, Thermo Scientific Porphobilinogen (PBG) Kit TR520001 (www.thermo.com/diagnostics). The test can be completed within 20 minutes. Your local laboratory can order the kit, by calling 1.800.528.0494 and press option 2. Patients often ask if they can perform the test themselves and the answer is “NO”. This test requires laboratory expertise.

Further diagnostic tests can only be sent to only a few specialized labs in the country. For example, the Porphyria Center at the University of Texas Medical Branch in Galveston Texas has a Porphyria Laboratory headed by Dr. Michel Lee. Biochemical tests for each of the porphyrinas can be performed there. If you are having difficulty getting a diagnosis, please call the APF 1 866 APF 3635 or see the website for a list of laboratories.

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**Thank You**

Mike Kensworthy and Matt Johnson

who will be meeting with the FDA as representatives for EPP patients. They will share their life long experience, including their recent experience as participants in the clinical trials using Afamelanotide. The FDA Office of Orphan Products Development will be filming a video of Mike and Matt for the reviewers and other FDA representatives to help them better understand the great need for treatment. Watch for the fall APF newsletter for an expanded story on their visit to the FDA.

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**National Rare Disease Day: February 28, 2011**

Each year Rare Disease Day has enjoyed an ever growing number of participating countries and more than a thousand patient organizations organizing events from tree planting to round tables, from marathons to art exhibitions. It has furthered rare disease as a public health priority, has shed light on the need for closer collaboration between patients and researchers, and now continues to underscore the challenges rare disease patients and their caregivers face. People living with rare diseases should be entitled to the same access and quality of care as any other patients. But today the reality is far from that. The rarity of patients, medical experts, knowledge and resources are aggravating the vulnerability of rare disease patients who are suffering from life threatening, debilitating, and chronic diseases. We are certainly not asking for more or better access and care than for other chronic diseases. To the contrary, we share the common cause of all chronic diseases. However, we believe that rare diseases is one of the most dramatic cases of health inequalities today both internationally and in particular in Europe. Therefore, the APF participated in activities nationally and joined a host of other countries around the world promote Rare Disease Day. For example, Stephanie Simpko manned a Living with Rare Disease Day table at her local hospital.