



Porphyria Research Is Starting Now...And You Can Help!



Left to right, Dr. Lawrence Liu, Dr. Robert Desnick, Dr. Joseph Bloomer, Dr. John Phillips, Dr. Montgomery Bissell, Dr. Manisha Balwani, Dr. Karl Anderson, Dana Doheny, Dr. Ashwani Singal, Dr. James Kushner, Dr. Brendan McGuire, Dr. Guilherme Perini, Desiree Lyon Howe.

Exciting things are happening in porphyria research! The second meeting of the Porphyria Clinical Research Consortium was held in January, with long-time porphyria experts, new colleagues, a grant coordinator and the APF in attendance. The purpose of the Consortium is to advance research and patient care in all of the porphyrias in a coordinated way throughout the United States, and research projects are starting now.

If you want to volunteer for clinical research, contact the APF so the Consortium doctors can contact you! There are five porphyria centers of excellence all participating in research so far: Mount Sinai Medical Center (NYC), University of Alabama (Birmingham),

University of Texas Medical Branch (Galveston), University of Utah (Salt Lake City) and University of California San Francisco. More study sites will be added as funding becomes available. Each of the study centers is recruiting patients with all types of porphyria. This means we need to hear from you, and you will need to give formal permission to have your contact information passed on to the study centers if you have not already done so. **Continued on page 5.**

Don't Be Left Out! Contact the APF so the Consortium can contact you! (See page 5.)

April 17—April 24, 2010 Is National Porphyria Awareness Week

National Porphyria Awareness Week is coming up soon! YOU can enhance public and physician awareness of the porphyrias in your community!

Monica Bennett Firchow is promoting her biography of her father Gene and his life with CEP; Jessica Melton is donating money to the APF through her gift basket business; Aubrey Brooks has recently received a bone marrow transplant for CEP and her family held blood and marrow drives and told her story through local media; acute porphyria patients are educating about treatment with Panhematin. What can you do to help?

- Hold an informational get-together at your child's school to help teachers understand the restrictions photosensitive children deal with;
- Volunteer your time and skills to the APF;
- Organize a lunchtime presentation for your coworkers about the importance of porphyria research for your life and your family;
- Ask to be included in the program for your worship services, or

invite congregants to share in information and conversation about porphyria;

- Purchase a stack of informational brochures from the APF, distribute them and collect funds for porphyria research at a local sporting event;
- Show the APF DVD, *Porphyria Live!* at an open house and talk to your friends and neighbors about what porphyria research means to you;
- Tell your story to local media;
- Donate funds to the APF to support life-saving research, training the next generation of porphyria experts, and educational programs for patients and physicians.

The APF has educational information about the porphyrias written by physicians who specialize in these diseases, and we have plenty of experience to help you plan your awareness week activities. Call us today! 1-866-APF-3635.

Little Aubrey Brooks



Aubrey Brooks was born with a very rare form of porphyria called Congenital Erythropoietic Porphyria (CEP), or Gunther's Disease. Less than a month after Aubrey's birth, parents Nichole and Doug began to notice that her diapers were tinged an orange-ish

pink. By the time she was a few months old, Aubrey was found to be anemic and began to develop blistering and scabs on her face. She was misdiagnosed for several months with impetigo—doctors even instructed her parents to take her out in the sun to dry her skin—and Aubrey's symptoms worsened.

Desperate for a diagnosis, Aubrey's mother drove her to Children's Hospital in Columbus, OH, two-and-a-half hours from home, and then to Pittsburgh, five hours from home. Through DNA and biochemical testing, Aubrey was diagnosed with CEP when she was seven months old. By that time, her parents had figured out that the sun and fluorescent lighting were dangerous for her, and while they waited for lab tests to be done it seemed that CEP was the only possible diagnosis remaining. The Brookses had bought, and received donations of, sun-protective clothing, covered the windows in their home and car to block visible light, and replaced all the light bulbs in their house with low-wattage incandescents.

CEP can cause extreme photosensitivity, and can lead to blistering, severe scarring and increased hair growth. Bacteria may infect damaged skin, and infection and phototoxic damage can lead to the loss of facial features and fingers. Red blood cells have a shortened life span in CEP, which can cause severe anemia. Fewer than 200 cases of CEP have been documented.

Aubrey's family worked with their local American Red Cross, which held its annual regional blood and bone marrow drive in Aubrey's honor. With a goal of 600 units of whole blood, the Media Day Blood Drive got 633 units and more than 300 marrow donor swabs (the swabs are used to match potential donors to recipients needing bone marrow transplants).

The drive was held on January 25 and Aubrey had a bone marrow transplant, a procedure that has been successful for some patients with CEP, the same week. Now Aubrey's family is hopeful that some day soon she will be able to go on outings with them, and that they will no longer need a babysitter to do something as simple as going to Wal-Mart. The APF and all our members wish Aubrey, her parents and baby sister a happy and a *healthy* year. We're standing with you and your brave little girl!

To read more about Aubrey and see updates on her fight against CEP: <http://aubreybrooks.com/>

Gene Bennett: Writing the Book

Monica Firchow does not have CEP, but she has learned about the disease while researching a biography of her father, Gene Bennett, who suffered from CEP his entire life. Monica invites readers to visit her family's updated website at <http://genebennett.net>.

Mr. Bennett made himself available as a research subject for the last 20 years of his life. He devoted much of his time to allowing doctors to learn from his experience and the effects of CEP on his body, so that they could better understand the disease and help other patients live healthier lives.



Gene Bennett in chair with five of his seven children. Monica is in the middle.

Monica's website is a continuation of her father's legacy. People with porphyria owe a great deal to Monica and her siblings, and to the Brooks family, for opening up their personal lives to help all of us and our doctors gain a better understanding of this disease.

Clinical Studies: What's in It for You?

All porphyria patients and their families can contribute to medical knowledge of these diseases by volunteering for research. Each of the five Porphyria Clinical Research Consortium centers is recruiting patient volunteers with all types of porphyria. Participation could include treatment trials, or simply visiting a Consortium clinic.

I have been lucky enough to take part in two clinical studies since my diagnosis with AIP in 1995. For me the most rewarding part of each project was the one-on-one time spent with a porphyria expert. As part of each study I was examined by, and discussed my history with, a doctor who had spent an entire career studying and treating the porphyrias. From a purely selfish point of view, I found it comforting to receive feedback on my experience with AIP, and advice about future treatment, from physicians who have seen more than a handful of cases. While I have always liked the doctors who care for me at my local hospital, speaking with an expert gave me added confidence that I am following the best course of treatment for me.

There is also the greater good to be served by taking part in a study. Patients who volunteer for clinical research can be proud to know that they are adding to medical knowledge about porphyria, making it possible for other patients to receive better care. Understanding that porphyria is a family disease makes this easy for anyone to relate to.

— **Mira Geffner**

Physician Education in 2010



“Those who know the most do the best” when it comes to living with a rare disease like porphyria, because it often falls to patients and their families to be informed about warning signs and proper treatment. Many doctors will never have had a patient with porphyria be-

fore you, so it’s important that you stay up to date on the correct diagnostic tests, know who the experts are in case your doctor needs to contact one for advice and have expert-authored information from the APF ready for your doctor to consult.

The APF has many additional resources for you and your doctor, and this year that includes a new, video-format Continuing Medical Education (CME) course in the Acute Porphyrias. This course fulfills one CME credit and is available for free and online. It features expert physicians Dr. Herbert Bonkovsky, Dr. Manisha Balwani, Dr. Brendan McGuire, and Dr. Karl Anderson. The CME video is titled *Acute Porphyrias: Recognition Through Follow-Up*: www.medscapecme.com/interview/acuteporphyrias.

Remember, too, there are other free CME courses related to the acute porphyrias in the Healthcare Professionals section of the APF website: <http://www.porphyrifoundation.com/for-healthcare-professionals>.

Additional acute porphyrias resources are available on the APF website: *Emergency Room Guidelines for Acute Porphyrias*, *Safe/Unsafe Drug Database for Acute Porphyrias*.

Note: The Healthcare Professionals section and the ER Guidelines have been translated into Portuguese.

Physician Conference Calls

Conference Call with an Expert is a new program the APF instituted for primary care physicians (PCP). How it works is a porphyria expert joins PCPs on a conference call where they can hear a presentation and have the opportunity to ask questions about their porphyria patients.

Recently, we held the first call with porphyria expert Dr. Karl Anderson as the presenter. Doctors around the world seek out experts, like Dr. Anderson, so the *Conference Call with an Expert* program provides them with that opportunity, particularly since it is not easy to contact one another during a patient-laden work day.

Please let your physicians know that they can participate in our *Conference Call with an Expert*. If they are interested, we will send information about the next conference call and instructions to participate on the call.

Our New Protect the Future Doctor



Dr. Guilherme Perini, our newest **Protect the Future** doctor, hails from São Paulo, Brazil where he is a hematologist at the Einstein Hospital. At present, Dr. Perini is a fellow in the Lymphoma Department at the MD Anderson Cancer Center in Houston, Texas. As

soon as his studies there end, he will join Dr. Karl Anderson at the Porphyria Center and Laboratory at the University of Texas Medical Branch in Galveston. During the recent Consortium meeting in Houston, Dr. Perini met Dr. Anderson and other experts and members of the *PtF* team. The gathering was his first opportunity to learn about the porphyrias and the upcoming research.

Dr. Perini attended medical school at the Federal University of Goiás and did his internal medicine and hematology residency at the University of São Paulo in Ribeirão Preto. His resume is very impressive and includes publications on thalassemia, leukemia, trissomy 8 and Behçet disease. It is our hope that his research and publications will include porphyria.

Shop and Benefit the APF

To have your purchases benefit porphyria research, when you shop at the APF website:

<http://www.porphyrifoundation.com/news/support-porphyrria-research-while-you-shop>.

Make Someone's Day Today is a line of gift baskets for all occasions from The Basket Lady. Make Someone’s Day Today donates a portion of each sale to the APF. See the APF website or go to <http://thebasketlady.gourmetfoodmall.com/StaticPage.php?pageid=1755>.

Raise money for the APF when you shop on Amazon.com by connecting through the APF website. When you connect to Amazon via the APF website, you will ensure that a percentage of the purchase price for each item you buy will go to support porphyria research:

<http://www.amazon.com/?%5Fencoding=UTF8&tag=ameriporphfou-20>.

Raise money for the APF when you buy *Phantom Variations: Tales of the Opera Ghost* at www.Lulu.com.

Desiree donated her book, *A Lyon’s Share of Trouble*, to the APF. All proceeds from the sale of the book are given to the APF. You can purchase the book about her story and those of many patients with every kind of porphyria on the APF website www.porphyrifoundation.com or by calling the APF. 1-866-APF-3635.

Protecting YOUR Future: What Does It Mean?

One day this month, I spoke with 25 people—all patients with different kinds of porphyria who had called the APF for help. One was a porphyria cutanea tarda (PCT) patient who was not healing despite several courses of phlebotomies and chloroquine. Another PCT patient had pain from the blisters and had no response to treatment. Both were anxious about their symptoms, but their doctors had no new treatment to offer.



Dr. Brendan McGuire and Dr. Lawrence Liu

Four of the people I spoke with had acute intermittent porphyria (AIP). They all suffered repeated attacks and frequented the emergency room. None had received any treatment but glucose. Treatment options like Panhematin were discussed but not offered, and their doctors were uncertain of what steps to take next.

I spoke with a mother whose son's erythropoietic protoporphyria (EPP) had made him so ill that he needed a liver transplant. She called to thank us for connecting her son's doctors with a porphyria expert who advised them in his care. Then there were the people who had been undiagnosed or misdiagnosed for years.

Each of the callers had a special problem that required knowledge beyond their own doctor's experience with porphyria, and this was only ONE day's worth of phone calls. The handful of experts in the U.S. cannot possibly respond to everyone individually. With most of our current experts approaching retirement age, WHAT WILL WE DO in the future?

Being very concerned about this situation, I asked members of our Scientific Advisory Board (SAB) to identify young physicians and scientists several years ago for the **Protect the Future** program to attract and train the next generation of porphyria experts. Young doctors are selected for excellent academic credentials and an interest in the porphyrias. With funding from the APF, experts are presently training 10 clinicians and two researchers in the United States, yet this number is still too small to meet the needs of the entire country.

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

If our experts retire before they can pass on their knowledge of porphyria, WE are the ones who will be hurt.

You can help!

- Ask your doctor 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 send your doctor instructions for joining the call.

- Encourage your doctor to visit the APF website, where they will find Emergency Room Guidelines for Acute Porphyrias, a Safe/Unsafe Drug Database for Acute Porphyrias, and two free, one-credit Continuing Medical Education (CME) programs.

- Help us train future experts through the **Protect the Future** program. When you renew your membership, make an additional donation, and make a note that it is for support of the **PtF**.

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.

Thank you to those who have already read and responded to pleas like this one. Like you, I am a porphyria patient and asking for money is a hard thing for me to do. However, there is no way to operate a home or a foundation without money and no better way to request your help than to ask openly. Please use the enclosed envelope to mark your membership and/or **PtF** donation. Thank you.

— **Your friend, Desiree**

Dr. Jennifer Guy



Dr. Jennifer Guy is a gastroenterologist and liver expert at the University of California San Francisco (UCSF) and San Francisco General Hospital. She is also one of a new generation of porphyria experts working and seeing patients with Dr. Montgomery Bissell in the UCSF Porphyria Clinic.

Dr. Guy is a wonderful asset to the porphyria Clinical Research Consortium. She has a degree in public health/clinical research in addition to an MD, and her current research projects include Hepatocellular Carcinoma (HCC, a type of liver cancer that is a risk for AIP patients) and access to specialty care. We have high hopes that this will be the beginning of a long relationship between Dr. Guy and the porphyria patients of California and the rest of the United States.

Gastroenterologists like Dr. Guy will be joined by geneticists, hematologists and dermatologists in the **Protect the Future** program. **PtF** doctors will study the porphyrias, see patients in clinic, build the National Porphyria Patient Registry and lead their own research projects in the porphyrias.

Continued from page 1 . . . **Porphyria Research**

The doctors spent much of the weekend developing questionnaires for long-term studies into each type of porphyria. A main goal of the Consortium is to build a registry and a core group of patients whose condition can be followed over an extended period of time. The doctors will collect similar information from all patients with a given type of porphyria and will use the data collected to answer the questions all newly diagnosed patients have:

- will my health improve and if so, when?
- what changes should I expect in my life from day to day?
- what precautions can I take and what advice should I pass along to my family members?
- what will happen when I decide to have children?
- what is the best course of treatment for me and what effects should I expect?

Naturally the doctors will reach the answers to these big questions



Dr. Joseph Bloomer, Dr. James Kushner

by answering many smaller ones. By volunteering to be a registry patient you can help the Consortium answer these universal questions.

The Consortium meeting also included discussion of how to include the **Protect the Future** participants in this work and this is where the APF, and our members, come in. The Consortium grant from NIH will pay for a wide variety of work—studies into genetics of each type of porphyria, clinical studies on PCT, acute porphyrias and others, and building the porphyria registry that will tie it all together.

There are also **Protect the Future** participants at every one of the study centers (and at other porphyria clinics around the country). These doctors work with experts in the porphyrias, studying these diseases, seeing patients and publishing with their mentors. Funding their ongoing training in the porphyrias is our responsibility and is not part of the federal grant funding. The **Protect the Future** participants are already quite advanced in their respective fields of medicine and science. Some are experts in genetics and other diagnostic tests, others are experts in liver disease in addition to being certified in internal medicine. All have completed extensive post-graduate training and are now taking the extraordinary step of committing to more training specific to the porphyrias. This is necessary because so few patients have porphyria that it is difficult for doctors to obtain experience.

The **Protect the Future** program is a means for these doctors to see porphyria patients while studying the diseases in ever greater depth and discussing their findings and future course with doctors who have made a decades-long study of the porphyrias. The APF and its members have every interest in continuing to find funding for this part of the Consortium program as these young doctors

are the next generation of experts who will care for us and our families!

The APF will also continue to communicate with our members about new consortium developments. Because of privacy considerations, the doctors cannot reach out to our membership directly when studies are coming up. It is very important that you remain in touch with the APF and keep us apprised of your contact information so that we can let you know about research opportunities that may interest you and may lead you to better health!



Dr. Manisha Balwani and Dana Doheny

Soon, APF members and their doctors will be able to view the Porphyria Rare Disease Clinical Research Consortium website. This will include some information about the porphyrias like what you find on the APF website, as well as additional information for doctors and updates on studies into each of the porphyrias. The Consortium website will be a great complement to the APF website, providing even more detailed information for physicians while the APF website continues to serve you with information that is relevant to your lives and accessible to a non-MD audience. Check back with the APF and make sure we have your current email address so we can keep you informed of developments.



**Dr. Montgomery Bissell,
Dr. Ashwani Singal**

How to Join the Registry... And Be Included In Future Research

Consortium coordinator Dana Doheny stressed that the best way to be included in the registry is to contact the APF and give us your permission to have the consortium doctors contact you. This is separate from the “Contact Registry” on the Consortium website, as that information is not currently relayed to the Porphyria Consortium.

HealthWell Foundation Fund Panhematin and Acute Porphyrias



HEALTHWELL
FOUNDATION®

Karen Eubanks applied to the HealthWell Foundation when the APF first announced that money was available to reimburse acute porphyria patients for some medical expenses. HealthWell has a fund dedicated especially for acute porphyria to help cover the high cost of treating these diseases.

Karen's experience with HealthWell has been smooth and positive, and she wanted to share it with others to help spread the knowledge that this option is out there for all acute porphyria patients.

Karen had been paying for and relying on COBRA benefits from her last job for several years when she signed up with HealthWell. She applied to HealthWell for help with the COBRA premiums, and once the application was processed received an initial payment covering her last three months worth of COBRA benefits. When it became clear that she would not be able to return to her demanding job as a customer service manager, Karen applied for and began receiving disability benefits and Medicare, and now HealthWell pays for her monthly Medicare premiums.

The process is easy:

Each year, Karen fills out the simple HealthWell application and receives her approval for benefits.

Each month when she receives her premium statement from Medicare, she sends the statement to HealthWell with a simple request-for-payment form. Within a few weeks she receives a full reimbursement check for her premium.

And that's all!

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

Jessica Melton: Turning HCP Around

Jessica Melton started having bouts of terrible pain in her belly along with other symptoms shortly after puberty. Her parents would take her to the emergency room when she was sick, yet the symptoms would often disappear just as mysteriously as they had appeared, making any diagnosis a challenge.



The first treatment Jessica received was a glucose IV, which she got repeatedly over about two years, up until the time she started receiving Panhematin at age 19. Now Jessica receives Panhematin regularly to keep her symptoms at bay, and for the most part she is feeling much better. In fact she has been feeling so well that she is getting her own business off the ground—a line of personalized gift baskets.

In an effort to translate her own difficulties into benefit for others, Jessica has generously promised to donate a portion of every sale she makes through her *Make Someone's Day Today* line of gift baskets to the American Porphyria Foundation. The APF is grateful for the support. We owe our continued existence to people like Jessica, who recognize the importance of reliable education and research on the porphyrias and are willing to help.

Jessica would also like to thank her parents for standing by her throughout her illness and today, and her doctor, who has been kind and understanding, and willing to help her find answers and treatment.

To see more information about *Make Someone's Day Today*, see: www.porphyrifoundation.com/news/support-porphyria-research-while-you-shop.

Living With Acute Intermittent Porphyria

My name is Bob and I have suffered from Acute Intermittent Porphyria most of my life. For many of those years there was no medicine or information on this disease. It wasn't until I was diagnosed with this strange disease that I began to relieve some of the pain. Over twenty years ago all that could help was a high dose of glucose. Then came an amazing medicine that allowed me to recover and stop this horrible pain. This miracle drug is called Panhematin. Yes it seems to cost a lot but without it my life could end. When I suffer an attack there is no other way to relieve it.

I'm 55 years old and otherwise healthy. I work every day as a police officer and hope to do this for many years. Desiree Lyon is one of those dedicated patients and spokespersons that have the drive to help all of us that are afflicted with this horrible disease. The problem is that there is not enough publicity to tell people what this disease is and how rare.

I also would like to thank Dr. Peter Tishler from Brigham and Women's in Boston, I owe my life to him. Maybe some day there will be a cure.

— Bob Quigley

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:

Kathleen A. Giacobbe for *John H. Giacobbe*; Shirley B. Fisher, Dorris J. Clapp for *Harvey Stansbury, Sr.*; Kathleen Toelkes for *Donna Pagano*; Sylvia Luehrs for *Debra Jean Wendland* and *Marvin Luehrs*; Olfet Agrama, Victoria Waddle, Gayle Brandeis for *Arlene Brandeis*; Joe L. Yager for *Arlene Yager*; Mike Gardner for *Deborah Lee*; Ralph Gray for *Fred Little Gray*; John H. Curran, Star L. Lundquist, Monica Haven for *Jane Walsh*; Diane Greer for *Bailey and Joe*; Joe Mayfield for *Euclid G. Mayfield*; Elaine Smuczynski for *Ed Marshall*; Mary E. Alfrey for *Jaunita Nanenkratt*; Vickie Gehm for *Judy Coley*; Stefanie Simko for *Walter Dudding*; Ronald and Norma Brown for *Matthew Brown*; Maureen E. Curran for *Margaret Curran*.

In Honor

Others have honored a loved one with a donation to the APF:

Mary Frances Donnelly, K. Lori Hanson, Grayfred B. Gray, Erica D. Gray, Eric S. Gray, Sarah Lawrence Pritchard, Angela Shiel, Robert E. Hendrix, Jolynn Foldesi, John Parks-Foldesi, Myrna Cartledge, Robert DuBard, Ian Gray, Gary E. Eyster for *Ralph Gray*; Diane J. Paquet for *Ken and Audrey Timper*; Mary Connelly for *Laura Cuddle*; Pamela Hughes for *Mary Ellen Monacelli*; Elizabeth Timper for *Diane Paquet* and *Kelli Quenzer*; Richard Drew for *Michael Drew*; Elaine Smuczynski for *The Smuczynski Family*; Dean Lodding Smiles, LTD for *Susie and James Young*; Anne T. Wilson for *Damela Flynn*; Diane M. Russell for *Craig and Nicole Leppert*; M. E. Whittenburg for *Jocelyn and Jamie Whittenburg*; Mira Geffner for *Dr. Karl Anderson, Dr. Montgomery Bissell, Dr. Joseph Bloomer, Dr. Robert Desnick* and *Dr. James Kushner*; Rhonald and Joyce Jenkins for *Mrs. Hayden Parker*.

The porphyrias are extremely painful and can be life-threatening. The American Porphyria Foundation is working to improve the health of those who suffer with these rare diseases 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.

Diana Ijames: Living with EPP

Diana Ijames was six years old and had suffered for two years with burning, itching pain when she was diagnosed with "a rare blood disorder." Doctors told her family that they didn't have a name for her condition, that very few people were known to have the disease and that Diana should stay out of the sun between 8am and 6pm. Diana did not find out that her condition is called Erythropoietic Protoporphyrria (EPP) until she was 20 years old.

Diana recalls that on one family vacation at Lake of the Ozarks in Missouri, she suffered a terrible reaction to the sun from being outdoors all day. Having no idea what was wrong with her and no means of relief, she started scratching at her skin, trying to soothe the itching and burning. Diana scratched so hard that she split open the skin on her arms. Trying to cool her burns, she started looking frantically for cold liquids she could pour on herself and eventually resorted to grabbing other vacationers' sodas out of their hands to pour them on herself.

Diana was initially pretty angry at the EPP diagnosis and at being advised to stay indoors. She had already suffered for years trying to live like a normal child and having terrible reactions to the sun over and over again. Both of her parents tan deeply, and she felt out of place being unable to tolerate the sun. Diana's father worked as a roofer all his life, spending every day out of doors. But looking back, the family believes Diana must have inherited EPP from her father's mother, who could never stand the sun.

Diana still has flare-ups of EPP from time to time, but for the most part, she can prevent EPP symptoms by using sun protective clothing—including hats, jackets and gloves. At one time Diana also used Lumitene faithfully. Lately she has stopped using Lumitene because where she lives in southern Missouri the summers last from March through September, so with the two months it took her to work up to a full dose of Lumitene each year she wound up taking the medication every day for most of the year and getting only a small amount of relief from the sun.

When Diana has flare-ups of EPP, there isn't much she can do other than wait it out. She turns the air conditioning in her house down to 65 degrees and uses cold compresses.

Diana and her husband have one child, who has no symptoms of EPP.

April 17 – April 24, 2010
National Porphyria Awareness Week

GET INVOLVED!

CALL APF TODAY!
1.866.APF.3735



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

Stay Up to Date on New Clinical Research! Porphyria Centers of Excellence across the country are recruiting patients with ALL types of porphyria now. Have you moved? Changed your phone number or email address? Make sure the APF has your current contact information so we can keep you informed.

Shopping for Porphyria Research: Amazon.com donates to the APF when you connect through our website; visit us at porphyrifoundation.com or contact the office to find out about other vendor offers.

Do You Have Acute Porphyria? Financial assistance with your medical bills may be available; see page 6 or call the APF for details. 1-866-APF-3635 (273-3635).

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.*

NONPROFIT ORG.
U.S. POSTAGE
PAID
HOUSTON, TX
PERMIT NO. 7279

Address service requested
4900 Woodway, Suite 780, Houston, TX 77056
AMERICAN PORPHYRIA FOUNDATION

