



National Porphyria Awareness Week March 29-April 5, 2008

YOU have the opportunity to enhance awareness of the porphyrias and to educate medical professionals in **YOUR** area. The APF will assist **YOU** and supply educational materials.

Below are suggestions to help you with **National Porphyria Awareness Week**.

- **TELL** your story to your local media. Television, newspapers, community magazines are looking for interesting stories about people who have faced a challenge, like porphyria, and coped with it.
- **SHARE** your knowledge about porphyria at your doctor's offices and local hospitals. Suggest a porphyria as the focus of a seminar, grand rounds or health fair.
- **INFORM** your physicians that we can send them an excellent slide presentation on acute porphyrias and information on the Continuing Medical Education (CME) course on the APF website. Such courses are free and are required as on-going training.
- **ASSIST** at upcoming medical conventions to help educate physicians on porphyria.
- **VOLUNTEER** your talents, like paintings, sculpture, weaving, for a raffle or to design a brochure or volunteer your computer and business acumen to assist with the educational programs of the APF.
- **ORGANIZE** a community race, car wash, bake sale, walk-a-thon or other fund raising activity.
- **SUPPORT** life-saving research through your efforts and donations.
- **JOIN** the IN TOUCH Network, discover new friends and host a meeting in your area.
- **SIGN UP** with your employer for a matching gift to the APF.
- **HONOR** your loved one with a donation to the APF for celebrations or with a memorial gift.

For information on how to participate in **National Porphyria Awareness Week**, please contact the APF: Toll Free: 1-866-APF-3635.

Other APF members helped make this week a great success by:

- **Wendy ver Voort** walked 141 miles to collect research funds for the APF.
- **Jenni Eberhardt** held a concert with pianist Steve Hall to benefit the APF.
- **Karen Eubanks** was one of the participants in the production of our terrific DVD.
- **Arunas Brizgys** "starred" in the Discovery Health program on television.
- **Lisa Kanscar** held fund raising and awareness events at her local hospital.
- **Mira Geffner** spoke at Ovation Pharmaceutical to help their employees appreciate the significance of their work.
- **Parker Snyder** created a display table at his wrestling championship in Montana.
- **Peggy Goudeau** donated her handmade quilts for the APF raffle.
- **Lauren Warren** ran an Ironman Race to help fund the APF.
- **Nita Busby** started a support group in CA.
- **Bob Barnes** volunteered his computer skills.
- **Justin Jones** wrote music.
- **Grace Warfield, Claire Sadowiczak, Charles**

Johnson and his family, Margret Johnson, Jack Finnegan, Beth Kepple, Danielle and Stephanie Frazzini, Debbie Pucharis, and Mathew Bohn, Margaret Johnson, and many others manned our exhibit booths at national medical conventions.

- **Kasey Knauff** filmed a CNN/CEP special.
- **Elizabeth Petersen** helped write and edit the newsletter and our first website.
- **Elizabeth** and **William Brouger** painted the APF Christmas Cards.
- **Monica Firchow** wrote a website on her father, Gene, whose case of CEP was widely read.
- **Dave McRae** spearheaded legislation in WA for handicapped parking for EPP.
- **Jennifer Gattoni** and **Tonya Love** started an APF internet forum.
- **Mathew Spaur** provided website guidance.
- **Megan Ralling** educated her own doctors.
- **Dan O'Reilly** garnered major media attention.
- **Charlotte de ne Guerre** wrote a porph novel.

An Important Anniversary

This anniversary is extremely important and very interesting. It began with people like, Marjorie Guthrie, the widow of famous folk singer, Woodie Guthrie, who died of ALS, Jack Klugman of *Quincy* television fame and a Los Angeles reporter. This year marks the 25th Anniversary of the Orphan Drug Act (ODA), a brilliant plan to provide pharmaceutical companies with incentives to develop drugs for rare (orphan) diseases, like tax credits and exclusive marketing rights.

Rare disease organizations, like the APF, joined together with Marjorie under the banner of the National Organization of Rare Disorders (NORD) to garner public support for the ODA. But public support for the ODA, at first, was sadly underwhelming. . . **UNTIL** a reporter for the *Los Angeles Times* wrote about the need for the ODA. Maurice Klugman, Jack Klugman's brother, read the article and insisted that Jack feature the issue on *Quincy*, his popular medical drama. Klugman aired two *Quincy* episodes spotlighting the desperate situation need for rare disease treatment, and he also testified before Congress. Klugman's involvement and our NORD campaign, created an enormous outpouring of support, which pushed the bill through Congress. President Ronald Reagan signed the Orphan Drug Act into law on January 4, 1983.

On February 16, 1984, Panhematin® for acute porphyria became the first Orphan Drug. It was originally manufactured by Abbott Laboratories, but when Abbott stopped making it, Ovation Pharmaceuticals saved the product. Since that time, 11 million Americans have benefited from treatments developed as a result of the ODA. 315 new treatments for rare diseases have come to market, and 1,749 products have been designated "orphans." Without the ODA, pharmaceutical companies may not be financially able to develop treatments for rare diseases because of the monumental cost of research, product development, FDA approval, user fees, production, and distribution. The FDA user fees alone can range from \$500,000 to \$1 million a year, which would be too costly for only a few hundred patients. Thus, many rare diseases still have no treatment. **So celebrate the 25th Anniversary of the Orphan Drug Act and Panhematin® as the first Orphan Drug.**

Hemodialysis: A therapeutic option for severe attacks of acute intermittent porphyria in developing countries

Murugesan R. Prabahar, Rajendran Manorajan, Devasahayam Sathiyakumar, Periyasamy Soundararajan, Maicha Jayakumar
Sri Ramachandria University and Sugam Hospitals, Chennai, India

An 18-year-old girl was admitted to the hospital with recurrent abdominal pain and convulsions. Earlier she had undergone an appendectomy for abdominal pain. On evaluation, she had hyponatremia (electrolyte disturbance), muscle pain, abnormal behavior, hypertension, and sinus tachycardia. She was diagnosed with acute intermittent porphyria after her 24-hr.

Medical Conventions

One of our major means of physician education is to exhibit our educational materials at two specific conventions, The American Association for the Study of Liver Diseases AASLD and the American Society of Hematology ASH. This year, APF member, Charles Johnson, headed the APF exhibit at the AASLD convention in Boston. Joining him were his family, Margaret Johnson, a non-family member and EPP expert, Dr. Micheline Mathews-Roth, who has helped us each time the conventions are held in Boston. Charles said they all enjoyed the experience of "teaching" doctors.

Beth Kepple, Stephanie and Danielle Franzinni, volunteered at the Atlanta ASH convention previously. Debbie Pucharis and Mathew Bohn were new and had these interesting observations:

Mathew – *"I was inspired by the genuine interest and sincere desire of the medical professionals in attendance to learn more about the different Porphyrrias. I felt the APFs presence at the ASH convention was successful in creating more awareness for this disease, which goes unrecognized."*

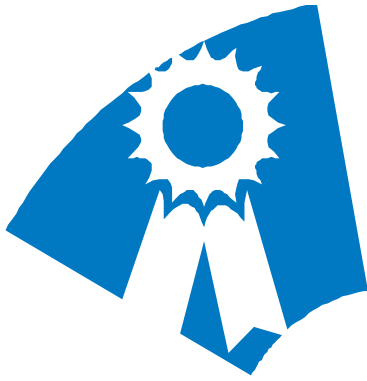
Debbie – *"I sensed a mutual level of frustration at the lack of knowledge and resources many of the doctors had in the testing and treatment of the many Porphyrrias. I was proud to represent the APF who made it possible to provide these doctors with pamphlets containing an overview of Porphyria, as well as direction on testing and treatment to better care for their patients."*



Seated left to right: Dr. Micheline Mathews-Roth, Margaret Johnson, and Bryan Johnson. Standing: Charles Johnson.

urinary porphobilinogen (pbg) and amino levulinic acid (ala) was very elevated, which was consistent with the AIP diagnosis.

After correcting her hyponatremia her doctors ordered hematin. She developed severe weakness, could not walk, and urinary incontinence before the hematin could arrive. Meanwhile, the doctors used dextrose, but it failed. Since hematin was not readily available, they considered other options, including hemodialysis, which had had good results in a few other cases. After receiving the hemodialysis, the young girl's abdominal pain and weakness subsided, and she was able to walk after four days. Her urinary retention also improved within four days. When the hematin arrived from the United States, she continued to improve and was released.

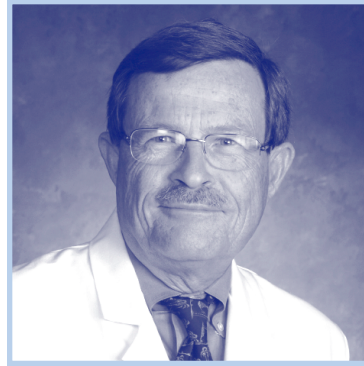


Ovation Award and APF Thanks

OVATION Pharmaceuticals, Inc., which manufactures Pan-hematin®, a treatment for the acute porphyrias, recently was named "Pharma Company of the Year for Small and Medium-sized Enterprises" at the 2007 Scrip Awards in London. This prestigious award honors out-

standing achievement by a growing pharmaceutical company over the past year based on excellent performance. Jeffrey Aronin, President and Chief Executive Officer of OVATION commented, "Our employees are honored to be recognized for our work and the success we've achieved bringing pharmaceutical innovation and important therapies to patients who need them."

The APF also thanks them for their tremendous support.



The *Houston Medical Journal* featured **Dr. Karl Anderson** in a special article entitled, *A Doctor's Doctor: A Rare Jewel*. His colleagues bestow the heights of accolades for his character and ability: humble, brilliant, dedicated to his patients, clinician and researcher of the highest quality, a treasure, a thoughtful and loving man. "He is the epitome

of what physicians aspire to be." Dr. Jay Pasricha, chief of Gastroenterology Stanford School of Medicine says about him, "Karl Anderson is a leading authority on porphyria in the world, an honor few can claim. His reputation and expertise draw references and queries around the country and the globe. His presence is a major asset for the University of Texas Medical Branch."

His NIH grant funded a degree granting program in Clinical Investigation at UTMB, the first such program in Texas. Dr. Anderson serves as the Director of the Division of Human Nutrition and Clinical Research Education, Associate Program Director of the General Clinical Research Center, Professor of Preventive Medicine and Community Health, Internal Medicine and Pharmacology and Toxicology, an extraordinary physician to be sure.

In 1962, Dr. Anderson received his undergraduate degree from the Johns Hopkins University in Baltimore and his medical degree from the Johns Hopkins University School of Medicine. His internship and residency was completed in Internal Medicine at Vanderbilt University Hospital in Nashville and a fellowship in gastroenterology at the New York Hospital, Cornell Medical Center in New York City.

Dr. Anderson has been a member of the Scientific Advisory Board of the American Porphyria Foundation for over twenty-five years and has served as Chairman of this Board for over twenty years. He has developed a major porphyria center and laboratory at the University of Texas Medical Branch in Galveston. Physicians from around the world seek his advice and assistance with their porphyria cases. Test samples from around the world are also sent for evaluation to the Porphyria Laboratory in Galveston for Dr. Anderson and his colleague, Dr. Chul Lee. It is not unusual for people to be tested repeatedly with no clear result. Many primary care physicians turn to members of the Scientific Advisory Board, like Dr. Anderson, for help. We appreciate him and are grateful for his decades of service to all of the patients he has helped, some of whom he has never met.

Boost Your Own Awareness: Looking for a way to get involved?

Host an IN TOUCH meeting for National Porphyria Awareness Week March 29-April 5.

Local meetings are a great way to meet and share stories with other porphyria friends and family in your area and hosting a meeting is a lot easier than you think.

Living with a rare disease can be lonely and frustrating. Doctors will talk with you about the symptoms of porphyria and suggest lifestyle changes, but they can't predict how the disease will affect you. Family and friends are essential support, but few of them will have shared your experience. Talking with other patients can help you sort out your own perspective on living with porphyria while you learn more about the disease.

If organizing a meeting alone seems overwhelming, have no fear. Ask a friend or relative to share the hosting duties. The APF will take care of some of the preparations for you: finding APF members in your area, sending out invitations and collecting the RSVPs. Of course, you can do extra work to make your meeting memorable, but in the end, most people who come will be grateful just for the opportunity to talk. All you really need to do is open the door when folks show up.

Contact Elizabeth at the APF to get started and help make your meeting a success.

IF YOU HAVE NOT SENT US YOUR EMAIL ADDRESS, PLEASE DO SO ASAP. THEN YOU CAN RECEIVE THE APF UPDATES. PLEASE SEND TO PORPHYRUS@AOL.COM.



Maria and Ray Bach-Baumgartner

After working many years, we moved to San Pietro, Italy to enjoy an idyllic life in a small town. Our house is surrounded by a garden, woodlands, hills and mountains. We have a little river called Lemina and nearby, the best ornithological Park in Europe with 2000 birds. But my beautiful, healthy life took a downward turn when I had to have hormones for a bleeding problem. After a few days on hormones, my blood loss stopped, but I began having very bad pain, confusion, depression, and pseudo-epileptic problems. I subsequently went weekly to the Emergency Center where I was given tranquillizers, which made me much worse. Instead of a diagnosis, doctors recommended a psychiatrist.

Fortunately, physician friends of ours read about the symptoms of porphyria, remembered my case and ordered tests. My results were positive for AIP, so I began heme arginate infusions. At the time, we had to get them in Helsinki, where it was manufactured. This was difficult, because it required ice and a special registration. I also had to have a Central Catheter for the infusions, because I have severely painful crisis often. The Italian health system, our friends, Drs. Coucourde and Reinaudo, and Ray, I can now get the treatment promptly in Italy.

To help other patients, I was a research volunteer for the synthetic enzyme, Porphozym™. Unfortunately, Zymenex did not pursue further development of this product. *Editor's note: Dr. Karl Anderson and Dr. Herbert Bonkovsky were the co-investigators for Porphozym in the US.*

My husband and I read books about AIP and corresponded with researchers worldwide. We also joined the American Porphyria Foundation. Moreover, we enjoy our lives, which is important to us; reading, writing, painting, gardening, cycling, and spending time with our wonderful friends, all important factors for a healthy life.

Gabby Carter

Lesley Carter wrote a poignant story about Gabby, her little daughter who suffered terribly and eventually died of one of the severe photosensitive porphyrias. Here is how it begins. The whole story will appear soon on the APF website.



"Gabrielle was born on the 28th of April 1982 at approximately 09:30 am on a beautiful sunny morning. Her skin actually fit her little body. Usually, as most mums know, babies are so wrinkly they look as if they need a good ironing! Gabby was absolutely perfect, so pink and healthy. She also had an abundance of silvery beige blonde hair. I remember thinking to myself that she had been aptly named, for Gabrielle means angel of God, and she was a little angel."

Within months, Gabby was seriously ill and hospitalized a great deal of the time. She was obviously in pain but no one seemed to know why. It was not until her porphyria diagnosis did they understand the pain, but by then, so much of the serious photosensitive damage had already begun and continued with devastating results. Gabby lived from one hardship to the next. Regardless of her circumstances, Gabby pressed on with the spirit of a champion. You can see in the poignant photo above, she had a "go girl" stance as she poised to run in the teddy bear race, her first such event. Despite the thick titanium dioxide on her face, what more beautiful little girl is there than Gabby dressed as a bridesmaid at the wedding of dear relative despite the thick titanium dioxide on her face?



Her mother's prayer when she died was equally moving. *"Oh God, I pray let her be happy. Let her laugh. Let her run to her little heart's content, barefoot and carefree, along golden shores, on strong little legs. Let her have no swollen tummy, no yellow eyes, skin or scabs. Don't let her feel the pain I still feel for her. Don't let her hear my cry."*

We sincerely appreciate Lesley sharing Gabby's story with us.

**YOUR SUPPORT IS NEEDED. THE APF IS FOR YOU.
PLEASE HELP WITH YOUR FINANCIAL DONATIONS, YOUR TALENTS,
YOUR SUGGESTIONS AND YOUR TIME.**



Debbie Puchoris: HCP and ME

I was happily married with a great career. I had purchased my first home and was living the "American dream" by age twenty-four. I never imagined that I would lose everything, become disabled and be in chronic pain requiring medication in order to have any quality of life. But in

1984, symptoms of Porphyria surfaced. Severe diarrhea forced me to the doctor, but it turned out that I was pregnant. Thus, my symptoms were thought to be from hormonal changes. Fortunately, I delivered a healthy baby girl. Unfortunately, the symptoms worsened.

I had my gallbladder and a pseudo cyst in my pancreas removed, followed by blocked arteries, a full bypass surgery, femoral artery bypasses, bowel obstruction, an abdominal aorta bypass and continued severe abdominal pain. During my many ER trips and hospitalizations, the doctors were baffled, particularly at my age. They blamed my pain on scar tissue from the surgeries. When removal of the scar tissue did not help, they suggested a complete hysterectomy. I agreed with the stipulation that I have one more child first. Getting pregnant was easy but the pregnancy was very difficult. I was hospitalized continually for various problems, including a bowel resection and was on total bed rest for most of the pregnancy. The pain was so severe, I required daily Demerol. Despite this, my son was born healthy. Because doctors couldn't be sure a hysterectomy would help, I opted for a monthly shot to shut down my menstrual cycle and alleviated some of the symptoms. I consequently agreed to have the hysterectomy and subsequent daily estrogen.

For many months, I improved but then the symptoms reappeared. Some doctors thought it was stress related, and others thought I was seeking pain medication. I was sent to a psychiatrist who prescribed anti-depressants, anxiety and sleeping medication. My symptoms just got worse. Then my bladder shut down, the pain spread to other parts of my body, and I became very agitated and confused. Doctors still found no physical cause, so my psychiatrist institutionalized me for many weeks and continued to prescribe more *unsafe* medications that made me worse. I deteriorated rapidly until I could not walk. I felt like I was dying, so I stopped my psychiatrist and my medications. To my surprise, I began feeling better and with physical therapy, I began to feel stronger.

A few years later, I relocated to California in hopes that new doctors could diagnose me. Instead I had the same routine; more pain, more psychiatric visits, more racing heart, more blood pressure problems. I even had to learn to catheterize myself when my bladder would not empty.

Because I developed a rash on my hands and legs that resembled poison ivy and had very fragile skin, a dermatologist

said I had Porphyria Cutanea Tarda (PCT) and told me to stop estrogen and scheduled phlebotomies. I felt hope at last. Although the diagnosis was incorrect, it spurred me to read about porphyria on the APF website. I also attended an IN TOUCH meeting where other porphyria patients convened for support. When I moved to Georgia, I asked my new doctor to order a test with porphyria expert, Dr. Joseph Bloomer. He diagnosed me with **Hereditary Coproporphrya (HCP)**, which is similar to AIP. I am now receiving Panhematin® treatments, so finally, I am doing much better. Yet, I still have chronic pain from nerve damage that occurred since it took so long to get diagnosed. It is still frustrating trying to find a physician, who knows about porphyria. At last, information from the APF has helped educate me and my doctor and helped me find Panhematin® treatment.



Robert Desnick, Ph.D., M.D.

We are very proud of APF board member, Dr. Robert Desnick. Dr. Desnick, who is the chair of the Department of Genetics and Genome Sciences at Mt. Sinai School of Medicine, has become chair of the Association of American Medical Colleges, a most prestigious position. Dr. Desnick also helped facilitate our new Porphyria Center/Clinic in Mt. Sinai Hospital, as well as the porphyria/DNA testing program. He recently reported that the porphyria clinic in NYC has been very successful since opening only a few months ago.

Dr. Desnick is internationally renown as a clinical, molecular, and biochemical genetics researcher. He serves as Professor of Human Genetics and Pediatrics, Chairman of the Department of Human Genetics and Director of the Institute of Genomic Sciences at Mt. Sinai School of Medicine in NYC. He has dedicated more than 30 years of his life researching porphyria and other rare disorders. Dr. Desnick has been a member of the Scientific Advisory Board of the APF for more than 25 years.

Please watch for Lauren Warren's story on the Discovery Health Channel on March 24, 2008.

Lauren was also interviewed by Montel Williams on his daily program. We do not have the dates of his program yet. Watch the APF Enews update for dates and times.

British Medical Journal — Acute Porphyrias

According to an article in the *British Medical Journal* (2000: 1647-1651 june 17) article by Dr. Allan Deacon and Dr. Timothy Peters, the following as factors that might precipitate an acute attack.

Factors that may precipitate acute attacks of porphyria

- **Drugs — barbiturates and estrogens (may be safe in replacement doses), progesterones, sulphonamides, methyldopa, danazol, diazepam, phenytoin, carbamazepine, sulphonylureas, chloramphenicol, tetracyclines, some antihistamines**
- **Fasting**
- **Smoking**
- **Alcohol**
- **Substance misuse — particularly marijuana, ecstasy, amphetamines, and cocaine**
- **Infection**
- **Emotional and physical stress**
- **Cyclic factors — premenstrual attacks are common**

They also discussed a number of other interesting issues about acute porphyria, which have been the subject of many callers at the APF. For example, latent porphyria can be confusing. Only 10-15 % (according to the article) of gene carriers develop symptoms. Interestingly, some people remain latent all of their lives, even in the presence of precipitating factors while other people have frequent attacks, when there is no precipitating factor. Only one third of the people with porphyria they researched had no family history of the disease. This may be due to the fact that so many of the gene carriers remain latent. In addition, attacks vary in severity and frequency, which can also be confusing. There are many factors that complicate the understanding of porphyria among patients and physicians. This is an example of why it is important to have physicians with expertise in porphyria and why the present porphyria experts are so valuable to train the next generation of experts through our "Protect the Future" program. Experts are critical to YOUR health. You can participate in the APF "Protect the Future" program by donating and helping us raise funds to train future experts. Call the APF and help the "Protect the Future" appeal.

Intermittent Unexplained Abdominal Pain — Is it Porphyria?

The **Clinical Gastroenterology and Hepatology** (vol. 5 no.11) published an Educational Practice article / CME exam on porphyria, "Intermittent Unexplained Abdominal Pain — Is it Porphyria?" It was written by Dr. Joseph Bloomer and Dr. Brenden McGuire, our APF *Protect the Future* expert in training at the University of Alabama Division of Gastroenterology/Hepatology, Department of Medicine, University of Alabama in Birmingham. After presenting a Clinical Scenario about a woman in an unexplained attack of abdominal pain, Drs. Bloomer and McGuire discuss the diagnostic guidelines, areas of uncertainty, management strategies and recommendations for their physician readers. This is an outstanding presentation and has been an excellent means of educating the medical professionals. Please contact the APF with the name and address of your physicians. We will send them an educational packet.



IN MEMORY

This has been the saddest period of the APF history with the loss of so many of our members. We extend our sincerest sympathy to the families

and friends who lost their loved ones. We also appreciate their generosity to the APF through their donations in memory of these beloved members:



We are also sad to announce the passing of *Dr. Shigeru Sassa*, who served on the Scientific Advisory Board. He was widely published in porphyria, particularly in the understanding of the mode of regulation of heme biosynthesis and molecular defects in the

human porphyrias. Among other discoveries, his lab reported the first molecular analysis of the gene defects in ALA dehydratase porphyria and erythropoietic protoporphyria. After a lengthy career as a prominent researcher at Rockefeller University in New York City, Dr. Sassa returned to Japan to serve as the Medical Director of Haplopharma, Inc.

I had many special occasions to be with Dr. Sassa, but one was especially memorable. A friend gave us his boat to sail around New York Harbor. We promptly invited Dr. Sassa, who was delighted to join us. At dusk we were sailing beside the Statue of Liberty. I was so overcome by the beautiful sight that I turned toward Dr. Sassa and said, *"I know that most porphyria patients do not have a chance to thank you and all the other porphyria experts, but I want to thank you for myself and all of them. Without doctors and researchers, like you, many of us would not be alive today to enjoy such wonderful sights."*

Donna Pagano, who died of porphyria, was an early member of the APF. Donna was dedicated to the mission of the APF and for many years, made monthly donations to the APF in memory of her sister *Arlene Yaeger* and *Millie O'Toole*.

Natalie Boren also passed away from porphyria at age 26. Natalie was also fondly remembered because she attended the APF patient education meeting in Houston only six months ago.

Other members were also honored with a gift to the APF in their memory: *Bettye Mayfield* was honored by her family. She was one of the earliest members of the APF and her son, *Joe*, serves on the board. *Jean and Laslo Molnar* for *Kalman Bonyhady*; *Rena and Fred Goldsmith* for *Kalman Bonyhady*; *Linda Suor* for *John Suor*; *Sophie and Edward Marshall* for *Susan Marshall*; *Sylvia Luehrs* for *Debra Jean Wendland*; *Joe L. Yager* for *Arlene Yager*; *Genevieve Reynolds* for *Lawrence A. Reynolds*; *Elaine Smuczynski* for *Helen Smuczynski*; *Vanessa Strange*, *Ovation Pharmaceutical*, *James Young* for *Dwight Howe*; *Zila Reichman* for *Dov Beru Diaman*; *Walter Cernik* for *Mary Cernik*; *Joe and*

Jack Mayfield for *Betty Mayfield*; *Dr. William H. Coleman* for *Gerry Busse*; *Ruth L. Werth* for *Rev. Frank J. Werth*; *Ralph M. Gray* for *Fred L. Gray*; *Donald Johnson* for *Peggy Lewis Johnson*; *Carol A. Hughes* for *Barbara Y. Styles*; *Jann Steelhammer* for *Dorothy Steelhammer*; *Geneva A. Burk* for *Dale Burk*. *Daniella Cunningham* and *Shelia Cole Nilva*, *Throckmorton Fine Art, Inc.* for *Peach Staszyn*, *Jane S. Cortell* and *Susan Larsen* for *Susan Arzouman*; *Delores Brazas* for *Wesley Brazas*.



IN HONOR

Ralph Grey was so inspired by *Megan Railling's* story on the front page of the Christmas newsletter that he sent each family member a copy. By doing so, they generously donated to the APF in his honor. *Tim and Amy Engelhardt*, children *Mathews and Angela*; *Heidi and Charles Moore*, children *Erica, Ryan, Lindsay and Lauren*; *Ivy and Brian Hassell*, children *Jen and Jon*; *Judith N. Clements*; *William Sims*; *Arlene De La Mora*; *Paula and Bob Hendrix*; *Lauren Hanson*; *Larry Pritchard*; *Myrna and Donald Cartledge*; *Eric S. Gray*; *Ruth Wilson*; *Gary E. Eyster*; *Kathleen Angela Shiel*.

We also thank the individuals who donated to the APF in honor of: *Elizabeth and Kenneth Timper* for *Diane and George Paquet*; *Richard Drew* for *Michael Drew*; *Betty J. Ross* for *Becky Ross*; *Diane J. Paquet* for *Audrey and Ken Timper*; *Kathleen E. Venter* for *Patricia Wright*; *Robert Quigley* for *Dr. Peter Tishler*; *Etta L. Insley* for *Dr. Herbert Bonkovsky* and *Desiree Lyon Howe*; *Bonnie R. Marcus* for *Dr. Lee Smith* and *Geri*, *Mary Glassom* for *Dr. Karl Anderson*.

Financial Aid Available

Finding treatment for the acute porphyrias can be difficult and expensive. Between the medications required to treat acute attacks, regular prescription costs and specialist doctor visits, expenses can run high even for those with good insurance. Patients without solid coverage face an even more daunting challenge. Luckily, the HealthWell Foundation offers financial assistance for all sorts of out-of-pocket medical expenses — including co-payments for doctor visits and prescription drugs, and health insurance premiums. HealthWell has a fund earmarked for treatment of the acute porphyrias. Fortunately, *Panhematin®* is among those covered. HealthWell will respond to your application within seven business days and grants funds based on medical and financial need. Let's get together and eliminate money as a barrier to your good health. Call 800-675-8416 or check: www.healthwellfoundation.org.

The HealthWell Foundation® is a non-profit, charitable organization that helps individuals afford prescription medications they are taking for specific illnesses. The Foundation provides financial assistance to eligible patients to cover certain out-of-pocket health care costs. We hope they can help you.



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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Also, the APF makes available to the public the Tax forms 990. For a copy contact the APF toll free 866 APF 3635.

What's New on the APF Web Site www.porphyrifoundation.com

PCT Research Project

If you have Porphyria Cutanea Tarda, you may want to volunteer for a research project for PCT. If so, please contact the APF office and ask for Desiree.

We have asked for patient volunteers for the last few months. You may already have contacted the APF and if so, that is great. However, if you have not learned about the PCT research study, please call the APF Toll Free at **1.866.APF.3635** or lyonapf@aol.com.

Remember the Drug Database

To have business cards with the Drug Database website printed on it for your doctors or Emergency Room staff, please contact the APF.

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