



Merry Christmas and Happy Holidays

*May your lives be filled with the happiness of family, friends, and good health
May your hearts be filled with love, peace, goodness and hope for the future
Yvette, Lelia, Carol, Elizabeth and Desiree*



Patsy Brady Hosts New York IN TOUCH Meeting

Over 20 APF supporters gathered recently at the home of Patsy Brady in Yonkers, New York for an IN TOUCH meeting. After introductions were made, each person shared their personal experiences of diagnosis and treatment. Patsy had an interesting story to tell as well. She was motivated to host a meeting, because her past AIP attacks were so severe that she was placed on a respirator for over six months before her recovery.

Since Desiree was in New York on other business, she also attended the gathering and introduced renowned porphyria expert Dr. Maureen Poh-Fitzpatrick, and her husband Dr. Brian Fitzpatrick. Dr. Poh has been a member of the APF Scientific Advisory Board since its inception 25 years ago and is highly recognized in the field of porphyria. She graciously accepted an invitation to speak at the NY IN TOUCH meeting. Although Dr. Poh is an expert in the photosensitive porphyrias, she gave an extremely informative and understandable overview of porphyria and then held a question and answer session so the attendees could ask questions related to their own cases. Generally, porphyria experts join the IN TOUCH meetings via teleconference but Patsy's group was fortunate to hear and meet Dr. Poh in person.

We thank Dr. Poh for sharing her valuable time and Patsy for the hosting this IN TOUCH meeting. Patsy has also volunteered to host another meeting in her Florida home this winter, so watch your ENews. If you are interested in hosting an IN TOUCH meeting in your area or joining the IN TOUCH network, please contact Lelia Brougher at 404-550-4880 or at email@boughers.com. Participating in the IN TOUCH network is our major means to help you make a connection with other APF supporters.

**Save the date: Sarah and Andray Korobovsky will host the next IN TOUCH meeting January 13, 2007.
For more information, please contact Lelia or the APF office.**

What One APF Supporter Can Do



Chelsea Kancsar

In this season's spirit of giving, Lisa Kancsar has given her time and energies in extraordinary ways to benefit porphyria educational and awareness programs. Her efforts began over a year ago in connection with the National Porphyria Awareness Week and have continued through the year. Lisa commented that we all had a responsibility to heighten awareness of porphyria and raise funds to help train new porphyria experts via our "Protect the Future" campaign in an effort to help ourselves. Below are a few resources that she and her daughter, Chelsea, used to accomplish their goal. Lisa encourages other APF supporters to explore the many ways that we, as individuals, can change the world of porphyria.

Some of the measures she used are as follows: approached hospitals to educate their staff about porphyria; initiated a Red Card account at TARGET so 1% of purchases can go to the APF; joined Kroger's and other stores pay back to charity programs where after \$5000 of purchases 5% can be donated to the APF; devised fundraising events at schools; approached stores to place APF collection bottles; initiated a community award cards and a community share program for charities. She has created purple ribbons and "hug coupons" to thank them for their interest in the porphyrias. Lisa has even taken on nursing duties and donated her salary for the "Protect the Future" program. The impact Lisa has made has been astounding, and we are very grateful for her efforts. Like Lisa, "If all of us would work toward this goal, we could make a great impact in our communities."



Donna Pagano

Donna Pagano lost her sister to porphyria many many years ago. Yet she has not forgotten that porphyria awareness and education is what was needed then and is needed now, so Donna sends a gift in memory of her sister, Arlene Yager, and Millie O'Toole every month of every year to help with this mission. Donna, who lives in Bothell, Washington, is a long-time member of the APF. In fact, several of the family members have also joined the APF and support our educational and research programs. Donna has not only made an impact with her donations, but she has also been an inspiration and a source of encouragement to her friends at the APF office.

We thank Lisa, Chelsea and Donna and all of you who have taken on the challenge to educate your communities about porphyria.

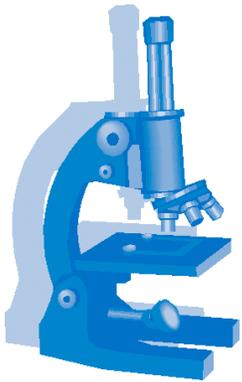


DR. CECIL WATSON

You may have never met or heard of Dr. Cecil Watson. However, if you have porphyria, you owe a great debt to him. Our lives have been transformed because of Dr. Watson's brilliant research and clinical work in the porphyrias. He was also responsible for teaching other physicians about porphyria and creating interest in the disease so that other doctors and researchers would continue his work.

Dr. Watson was born in 1901 in Minneapolis, Minnesota of Irish parents. Both provided Dr. Watson with rich intellectual nourishment and stimulation and engendered in him a lifelong passion for literature and history. According to Dr. Claus Pierach, who studied and worked with Dr. Watson for many years, "His classical education left Watson with an unusually broad range of knowledge in the liberal arts and endowed him with a superb command of the English language that, in his professional life, was reflected in the brilliance of his lectures and the lucidity and elegance of his scientific publications."

Dr. Watson was ahead of his time in chemical and biochemical exploration, which was key in his pioneering scientific work on the metabolism of hemoglobin, porphyrins and bile pigments. He began his study of liver functions in 1930 in Germany under Hans Fischer, the Nobel prize-winning chemist. He continued his research in the United States at the University of Minnesota, where he and Dr. Samuel Schwartz discovered a fundamental test for porphyria, the Watson-Schwartz tests. He was also the author of more than 350 scientific papers. People who knew and loved him agree that his enthusiasm and insatiable intellectual curiosity stimulated his medical students and colleagues as to the importance of what they learn at the bedside as well as in their laboratory discoveries. Together we can continue Dr Watson's life-saving work by contributing to the APF's "Dr. Cecil J. Watson Protect the Future" program to train new specialists.



CLINICAL TRIALS: Listed below are websites to read about past clinical research trials. If you are interested in participating as a research volunteer, watch the newsletter for upcoming projects:

- [Study of the Pathogenesis of Porphyria Cutanea Tarda](#) - This study has been completed (Current: 08 Jun 2006)
- [Risk Factors of Porphyria Cutanea Tarda \(PCT\)](#) - This study has been completed (Current: 08 Jun 2006)
- [Studies in Porphyria IV: Gonadotropin-Releasing Hormone \(GnRH\) Analogues for Prevention of Cyclic Attacks](#) - This study has been completed (Current: 08 Jun 2006) - luteinizing hormone-releasing factor
- [Studies in Porphyria I: Characterization of Enzyme Defects](#) - This study is currently recruiting patients (Current: 08 Jun 2006)
- [Phase I/II Study of Heme Arginate and Tin Mesoporphyrin for Acute Porphyria](#) - This study has been completed (Current: 08 Jun 2006) - heme arginate,tin mesoporphyrin
- [Studies in Porphyria III: Heme and Tin Mesoporphyrin in Acute Porphyrias](#) - This study has been completed (Current: 08 Jun 2006) - heme arginate,tin mesoporphyrin
- [Phase I Study of Tin Mesoporphyrin in Patients on Long Term Heme Therapy for Prevention of Acute Attacks of Porphyria](#) - This study has been completed (Current: 08 Jun 2006) - heme arginate,tin mesoporphyrin
- [Phase I Study of Heme Arginate With or Without Tin Mesoporphyrin in Patients With Acute Attacks of Porphyria](#) - This study has been completed (Current: 08 Jun 2006) - heme arginate,tin mesoporphyrin
- [Study of Nutritional Factors in Porphyria](#) - This study has been completed (Current: 08 Jun 2006)
- [Diagnostic and Screening Study of Genetic Disorders](#) - This study has been completed (Current: 08 Jun 2006)
- [Study of Cysteine Hydrochloride for Erythropoietic Protoporphyrin](#) - This study has been completed (Current: 08 Jun 2006) - cysteine hydrochloride
- [Phase III Study of L-Cysteine in Patients With Erythropoietic Protoporphyrin](#) - This study is no longer recruiting patients (Current: 08 Jun 2006) - cysteine hydrochloride 2006



Arrivederci Roma 2006 Hello USA 2008

The First International Porphyria Patient Meeting in Rome was not only an outstanding educational experience, it was also a global Friendship Fest. As guests of Associazione Malati di Porfiria (AMaPo), the Italian porphyria patient organization, APF friends enjoyed wonderful camaraderie with new friends from around the world.: Ieda and Bene Bussman (Brazil), Lelia and Brent Brouger (Atlanta), Suzette Cowles and her daughter, Valerie Braginetz (Denver), Ed Geffner (New York), and the California delegation, David Lang, Doris and Jack Stevens, Mira Geffner and her husband Paul, and Texans, Dr. Karl Anderson, Desiree Lyon Howe and her husband, Dick. Those of you, who did not have the opportunity to attend this meeting, can join us at the Second International Patient Meeting. The APF will sponsor this meeting during the summer of 2008 in the USA. At present, we do not know where the meeting will be held, but we do know that we need your help. Look for more information in the March newsletter.

We sincerely appreciate the efforts of **Dr. Gianfranco Biolcati**, who heads the porphyria center in Italy, and **Simona Pavia**, the President of AMaPo, who organized this outstanding conference with attendees and lecturers from Hungary, Italy, France, Germany, Norway, England, Switzerland, the United States, Brazil, Spain, India, Ireland, and the Czech Republic. Simona opened the conference by asking patients and the leaders of the patient organizations to share their experiences.

Among the interesting stories was one given by a Hungarian physician who suffered a critical AIP attack. Although she was a radiologist and worked in a hospital every day, she was still shuffled from doctor to doctor; each of whom repeatedly misdiagnosed her and prescribed unsafe medications which led to the severe attack. She was eventually diagnosed and re-covered after being given heme arginate (Normosang). Unfortunately, however, she could not afford the prophylactic monthly infusions of heme arginate to keep the attacks at bay, so she has continued to suffer major difficulties in her life and work. Fortunately, in the US, Ovation has made it possible for those who need Panhematin (heme therapy) to receive it. Surprisingly, although European countries have national health care, people cannot always receive heme arginate because of its tremendous cost.

Particularly poignant for me was the opportunity of meet Rasa from India and Bene from Brazil, whose lives were saved through APF intervention. Rasa, who is only 16 years old, had been in the ICU for three months before her family contacted the APF. Since Bene's story was similar story, both women expressed their gratefulness to the APF for its help.

Dr. Biolcati opened the scientific lectures with an excellent overview of the porphyrias. He then introduced the other presenters, who were among Europe's most distinguished scientists and porphyria experts:

Dr. Xiaoye Schneider—Molecular Biology

Dr. Elisabeth Minder—EPP

Dr. Pamela Poblete-Guitierrez—PCT

Dr. Caterina-Furlan—Liver's Role in the No Acute Porphyrias

Dr. Jean Charles Deybach—European Initiative & AIP

Dr. Jorge Frank—VP and HCP

Dr. Karl Anderson—Therapy of the Acute Porphyrias

Aside from the educational value, these lectures were of great interest to me because they helped address several points of confusion among some porphyria patients who were concerned that there were differences in testing and treatment between Europe and the United States. One subject of confusion is DNA testing. Some people think that DNA testing is available in Europe with-out biochemical evidence and that their testing ranges for screening and diagnosing the acute porphyrias are different than in the US. According to the European experts, they do NOT perform DNA tests without biochemical evidence. The evidence means screening for the acute porphyrias determined by elevated porphobilinogen PBG.

Interestingly, Dr. Deybach expressed concerns about who would be the future experts in the US when the present group retires. He and the European experts have worked with their US colleagues for over 25 years. I explained that this was exactly the object of our "Protect the Future" campaign to fund new porphyria expert trainees for the future.



— APR MEMBERS —

(l to r) Valerie, Ieda, Bene, Suzette, David

**JOIN THE IN TOUCH NETWORK
AND RECEIVE THE NAMES
OF ALL OTHER IN TOUCH MEMBERS.**

**CONTACT THE APF:
1.866.273.3635**



Jennie Eberhardt APF Goodwill Ambassador 2006

Jennie Eberhardt, who hails from Racine, Wisconsin, recently received the **2006 APF Goodwill Ambassador Award**.

Jennie says she is about building bridges; bridges to knowledge, better health and better relationships. She has embraced these challenges by offering her time, energy and extended hand of friendship to help both patients and doctors in her community. Congratulations!

offering her time, energy and to help both patients and doctors in her community. Congratulations!

Recently, Jennie, her husband, Rich, and their friends, Ruta Jaras, Lynn Shulak, pianist Steve Hall, and singer Corky Morgan organized an extraordinary concert to benefit the APF research program. Each of them are to be commended for their efforts on behalf of the of the APF. Jennie and her crew are already planning next year's concert, so if you would like to help, please contact Jennie at JeniLynEbe@aol.com.

Rotterdam 2007



For Scientists and Clinicians Rotterdam will be the site of the next **Porphyrins and Porphyrins Conference**, an International meeting on Porphyrin Metabolism and the Porphyrins, which will be held from April 29-May 3, 2007. These scientific meetings are generally held every two years and have been organized in cities around the world by porphyria experts and researchers. These gatherings provide an opportunity for the clinicians and researchers to share their expertise. The topics will include heme synthesis enzymes, heme degradation, iron related topics, porphyria diagnostics, therapies, clinical issues, drug porphyrinogenicity and phoyto-dynamic therapy.

The aim of the Rotterdam meeting is to create an informal atmosphere to share lectures and poster sessions for both the experienced and new researchers in the field of porphyria and porphyrin metabolism.

Rotterdam is a multicultural city with the largest port in Europe. The renowned museums and modern architecture are part of Rotterdam's attractions as are the nearby cities of Delft, Leiden and Amsterdam. If you would like to learn more and/or register, please see: www.2.eur.nl/fgg/emco/porphyrias2007.

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Christmas and Holiday Greetings from the APF Staff
Elizabeth, Desiree and Yvette



Lyon's Share

The APF staff are "patient navigators" to help you navigate through the many barriers to proper diagnosis and treatment of the porphyrias and to help you learn what is happening around the country in the world of porphyria. Being an APF "patient navigator," is a gratifying experience, because it allows us the privilege of meeting and communicating with so many of you. Imagine our satisfaction as we assist you at some of the most difficult times of your lives.

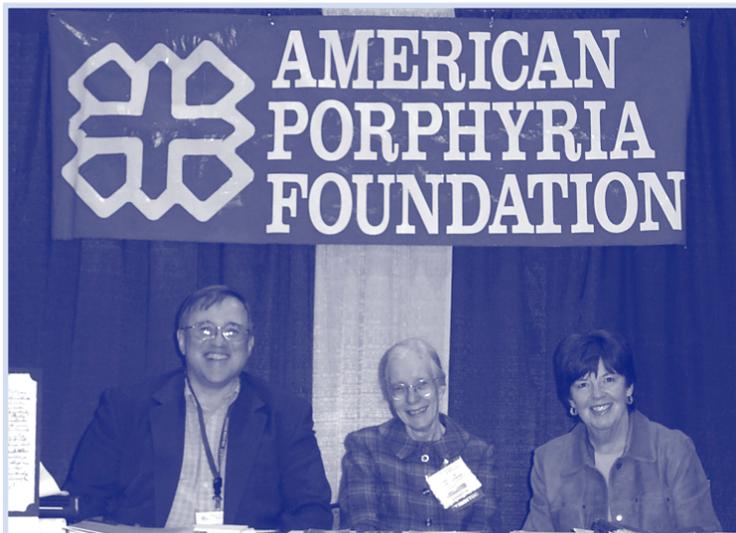
As a "patient navigator," I can relate what I have learned by talking with porphyria experts around the world. First, even physicians in Europe were concerned about how the APF could help assure that there would be new experts when the present specialists retire. Experts around the globe have worked together for almost three decades, so they know each other well and know the situation in each country. I assured our European friends that we established a "Protect the Future" campaign to train new doctors for the future to treat and diagnose porphyria.

We have now identified five doctors whose present training is synergistic with the extra training needed to become a porphyria expert. We need you're your help, however, to raise the funding necessary to train these doctors, particularly while we have the present experts ready and willing to facilitate the training.

Each of you has been endowed with astounding talents and resources. I would ask that you use those talents and resources to gain funds for this training.

You may not understand this most urgent need, but that is my fault. If I were better at my job, I could enlighten you better about how serious the situation is. Please ignore my inability and address the problem that we need experts for the future and help us by donating finances with a check or credit card number or donating your talent for this mission. Please help!

**Who Will Guide Our Primary Care Physicians
If We Don't Protect the Future**



your participation. If you are interested in volunteering for an upcoming particular convention, please respond and we will then acquaint you with the process to exhibit.

The American Association of the Study of Liver Diseases Meeting Boston, MA

We sincerely appreciate the efforts of (l to r) Jack Finnegan, Dr. Michelene Mathews-Roth and Margaret Johnson who manned our APF exhibit booth at The American Association of the Study of Liver Diseases held in Boston recently. Almost ten thousand physicians and medical professionals attended this most prestigious convention. Since exhibiting at medical conventions is a major means of promoting physician education for the porphyrias, we are careful to choose which meetings are most important for porphyrias.

Manning a booth is also an interesting experience for those APF friends who volunteer to distribute information to the physicians and talk with them about porphyria. When there is a medical convention in your area, we will send a notice and a request for

The American Society of Hematology was also held a few weeks ago in Orlando, Florida. The APF exhibits at this meeting because hematologists are the doctors who end up with the majority of acute porphyria patients. APF supporters, Marianne Gennetti and Claire Sadowiczak helped facilitate our educational programs, including the exhibit booth at this meeting. They found the ASH meeting to be an "exciting" and "worthwhile" experience. Watch for more information about the ASH convention in the March newsletter. Hopefully, you will participate when a medical convention is held in your area.

The National Porphyria Awareness Week

Many of our supporters ask why their doctor did not diagnose them timely. One of the reasons is that The **National Porphyria Awareness Week** is February 17 – 24, 2007. You can help enhance awareness of porphyria through the many services and programs of the American Porphyria Foundation. The upcoming **National Porphyria Awareness Week** is a wonderful opportunity to accomplish this goal, particularly in the medical community. By spreading information about porphyria, the public and physicians alike will more readily recognize the need for better diagnosis and treatment. Here are a few suggestions for your participation.

***SHARE** information about porphyria at your doctor's offices, local hospitals, newspapers, television stations. These opportunities generate greater public awareness and, in turn, improve early recognition of the disease.

***HELP** at a medical convention. You can enhance physician education about the porphyrias by manning an APF exhibit booth and distributing important information about the disease.

***BUILD** a network of understanding with other people with the disease.

***VOLUNTEER** your time and talents to help improve the awareness and educational programs of the APF. Fund raising activities are important to our mutual mission.

***SUPPORT** life-saving research through your financial donations and/or volunteer to participate in a research program.

***APPROACH** the media with your story. A good human interest story often opens the doors to the media more than any fiction piece.

***JOIN** the IN-TOUCH Network and enhance your own knowledge of porphyria while discovering new friends.

***DONATE** your time and finances to improve APF educational efforts.

***SIGN UP** with your employer for a matching gift to the APF.

***SUPPORT the APF and support each other.** Together we can be a force to promote awareness and education. Over this past year, physician awareness has escalated exponentially. To participate in this effort via **The National Porphyria Awareness Week**, please contact the APF 713-266-9617.



New Facility Opens

Ovation Pharmaceutical was given the green light from the US Food and Drug Administration (FDA) to begin manufacturing **Panhematin** at Cardinal Health's new sterile facility in North Carolina. Ovation specializes in developing medically necessary therapies in areas of unmet medical need. Thus,

when Abbott ceased to be interested in manufacturing Panhematin, they sold the product to Ovation.

However, when Ovation purchased Panhematin from Abbott Labs, they were still required to maintain the FDA mandates which had previously been given to Abbott. One such FDA mandate was to have Panhematin manufactured in a new facility with particular FDA requirements. This new facility is the fulfillment of that promise to the FDA. Dr. Joseph Bloomer, Professor of Medicine and Director of the University of Alabama Liver Center commented about the opening of the new facility. *"The support from Ovation and Cardinal Health is critical to ensuring product supply as Panhematin is the mainstay of treatment for acute porphyrias."*

As part of the opening ceremonies, APF member, Mira Geffner, briefly spoke to the 82 employees. Mira has successfully used Panhematin infusions for many years to halt her severe AIP attacks. She explained the importance of their work via teleconference to help them understand the life-saving nature of their work.

Since Panhematin is the only FDA-approved therapy for acute porphyria, it is essential for the many patients who suffer severe attacks and for those who have the infusions to prevent cyclical attacks. In fact, in some cases, if left untreated, porphyria can lead to long-term or permanent paralysis, coma or even death. Therefore, we are grateful to Ovation for the many hurdles they have overcome to assure that Panhematin is provided to everyone in need.

Ovation maintains an assistance plan for people who need Panhematin and are having difficulty securing it or are experiencing insurance issues. If you are in such a situation, please contact the APF for more information.

Also, the APF would like to commend Ovation for their ongoing global commitment to assist suffering people. Ovation donated nearly \$1.3 million of high-need medications to AmeriCares, a nonprofit disaster relief and humanitarian aid organization for children suffering from lead poisoning in Kosovo, where that problem is severe.

**OVATION PATIENT ASSISTANCE PROGRAM
1-800-455-1141**



Drug List and Drug Study

Many of you participated in the recent drug study with Dr. Peter Tisher. Dr. Tishler is continuing to work on the drug lists and sends his thanks along with ours for your assistance in this endeavor. Published drug safety lists are by no means infallible. The information in them is gleaned from three sources: published and anecdotal reports of experience in patients with porphyria, results of laboratory testing in porphyric animals, and exposure of cell culture systems to drugs with measurement of the induction of porphyrin synthesis.

Thus, those drugs observed to be porphyrinogenic by experience or in these test systems will be considered as potentially unsafe on most porphyria drug lists. On the other hand, some drugs shown to induce porphyrin synthesis have been used safely in people with porphyria. Similarly, clinical experience may be misleading, in that drugs may not have been given singly or other factors may have been operative in precipitating the acute attack. Porphyrin patients' sensitivity to drugs is also variable; those with AIP tend to be less tolerant of drugs than those with VP. Each of these factors make it very difficult to construct a set drug list that can be used without reservation. It is very important to apply caution when using any of these lists with safe and unsafe medications and to check with your physician. These lists are only helpful guides and not set standards.

Urgent Needed \$12,760

There is a very serious problem that you can solve. The **High Performance Liquid Chromatography** (HPLC) is a complex diagnostic instrument which is essential for the diagnosis of different types of porphyria. The HPLC separates porphyrins and is, therefore, important for the differentiation of the different types of porphyria.

The HPLC consists of three major components to operate properly. Unfortunately, Dr. Chu Lee reports that the HPLC instrument at the UTMB Porphyria Center is no longer operable. One of the major components, the fluorescence detector, is outdated and must be replaced before the instrument can be operational again. The needed component, the Waters Fluorescence Detector-Model #2475, is extremely costly; to be exact **\$12,760**. Since the laboratory does not have the funding to replace this important component, Dr. Lee has not been able to run samples and thus, perform the tests necessary for specific porphyria diagnosis. Your help is needed to purchase this most important component for the HPLC instrument. Please contact the APF and ask that your gift be applied to the HPLC. Thank you.

JOIN THE APF ENEWS . . . CONTACT THE APF: 1.866.273.3635

Rome Continued:

*Because we receive questions asking if there are differences in treatment and diagnosis in Europe and the US, we are including **Mira Geffners**'s outstanding account of the meeting:*

I was excited to attend the Rome meeting. The most striking impression of the conference was of the compassion and generosity of the physicians and scientists who attended. I want to thank all of them, as well as Simona Pavia and the Associazione Malati di Porfiria (A.Ma.Po). The clinical physicians and laboratory researchers at the conference gave generously of their time in traveling to attend the conference and were quite open to patient questions and suggestions. In the majority of sessions these doctors from France, Germany, Italy, the Netherlands, Switzerland and the United States, gave talks ranging from clinical issues to the genetics of, treatments for, and lifestyle/health issues relevant to all of them.

In a free-flowing exchange after each talk, patients both aired their own concerns and heard the speakers respond to: each others' presentations and elaborate on different approaches to treatment. It was a singular experience to meet with such an impressive group of Porphyria scholars in one place, brought together for the purpose of educating patients about our disease, its treatment and prognosis.

There was also broad international agreement on how to diagnose and treat the various porphyrias. The doctors emphasized the importance of confirming a biochemical diagnosis through urine, stool and blood samples whenever porphyria is suspected. Biochemical diagnosis through a reputable porphyria lab is the

essential first step in getting proper treatment for and managing the disease. The doctors further urged DNA testing for confirmed porphyria patients so that family members can be diagnosed through DNA testing before they become ill. Once one family member has a biochemical diagnosis of porphyria and a genetics lab has analyzed that patient's blood, DNA testing is sufficient to diagnose other relatives. All the doctors at the conference who treat the acute porphyrias recommended that acute attacks be treated as early as possible with heme therapy, either Panhematin or Normosang (heme arginate in Europe). People should remember that acute porphyria attacks can be deadly, and when left untreated can lead to seizure, paralysis and possibly death. Even less serious attacks can result in moderate to severe pain, nerve damage, etc.

Both Prof. Deybach of the Hospital Louis Mourier in Paris and Dr. Anderson of UTMB-Galveston spoke about the need for patients to be active in supporting future Porphyria research. Dr. Anderson pointed out that in the United States, while most patients may not be able to donate sums that will fund medical research, their contributions can make it possible for patient associations to lobby the government for research funds and treatment approval. It was inspiring to see the youth and enthusiasm of patient organizations attending the conference. Expanding this network across international borders should be a help to all patients.

If you would like to read other accounts of this meeting and view some of the photographs, please see the APF website.



In Memory

It is difficult at any time of the year to remember the loss of a loved one, but it is especially painful during this Christmas and holiday season. We want to express our sympathy to all of our APF friends who have remembered their family and friends through gifts to the APF.

- * Donna L Pagano in memory of Millie O'Toole and of Arlene Yager
- * Diane and George Paquet in memory of Stephan Kurjanski
- * Janet E Tarpine in memory of James Vincent Marston
- * Anna Mae Tarpine in memory of James Vincent Marston
- * James Stanislaw in memory of Clara Zarmebea
- * Gloria R Sheehan in memory of Paul Sheehan
- * Louis & Joann Barnes in memory of James Vincent Marston
- * Michelle Letkemann in memory of Olga Rust
- * Beatrice Davis and Mark Talkington in memory of David Lee Talkington
- * Whitman West in memory of Cheryl West.
- * Maria Hollcroft in memory of her beloved brother, John (Johnny) Cicchirillo
- * Rose Jeans in Memory of her mother Patricia (Pat) Mastropier Jeans

In Honor

These friends honored their loved ones with a gift to the APF.

- * Ada Trilling in honor of Sara and Dennis Branscome
- * Walter Frank Cernik in honor of Michelle Letkemann
- * Judy Kitchen in honor of Dr. Kenneth Astrin





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 on the APF Web Site www.porphyrifoundation.com

National Porphyria Awareness Week: Join in the effort to heighten awareness among the medical community. You can make an enormous impact in your community by contacting your local hospitals and ask that they organize an in-service. See the website for more suggestions on what you can do.

DNA Testing: If you are interested in DNA testing, please contact the APF DNA Laboratory at the Mt. Sinai Medical School Department of Human Genetics. The APF website relates the parameters for testing.

The Second International Porphyria Patient Conference: With your help, The American Porphyria Foundation will host this next international conference in 2008. APF supporters will join friends from other porphyria organizations from around the world. Although it is a year away, we can be underway with your help.

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