



Dr. Jennifer Lai, Newest Protect the Future Trainee

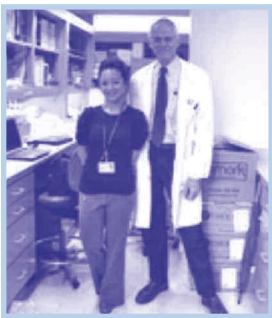


APF would like to give a warm welcome to the newest member of our APF medical professional team, Jennifer Cindy Lai, M.D. She is being mentored by Dr. Montgomery Bissell in the *Protect the Future* program as part of our initiative to train future porphyria experts. Currently a fellow in Gastroenterology at the University of California-San Francisco, Dr. Lai's hepatology research and interest will be a great service to the APF. After matriculating from Stanford, she entered Tufts University School of Medicine, earning both her M.D. and her M.B.A. During her residency at New York Presbyterian Hospital-Columbia, she won awards for Excellence in Clinical Teaching and Excellence in Ambulatory Care.

In addition to her contribution to six peer-reviewed articles, Dr. Lai has participated in a number of presentations, including most recently "Bad to the Bones: What You Need to Know About Bone Disease" at the 2011 UCSF Gastroenterology Grand Rounds. Currently a member of both the American Gastroenterological Association and the American Association for the Study of Liver Disease, among other organizations, she volunteers her free time at the Hepatitis B Free Clinic at UCSF-Mount Zion Medical Center as a volunteer clinic preceptor. Dr. Lai's knowledge and interest of diseases afflicting the liver will undoubtedly be helpful for the growth of the American Porphyria Foundation's medical research and efforts. When asked about her interest in porphyria, Dr. Lai explained, "There is a lot of information, and mis-information, on the internet and in the community about AIP, and I saw how important it was for patients

and their families/friends to have an accurate diagnosis about the etiology of their pain and suffering in a timely fashion. Only after training with Dr. Bissell did I begin to realize the spectrum of clinical presentations of the porphyrias not just AIP." Welcome, Dr. Lai!!!

Dr. Montgomery Bissell



Dr. Bissell is a member of the American Porphyria Foundation's Scientific Advisory Board since 1982. He is Professor of Medicine and Director Emeritus of the Liver Center at the University of California, San Francisco (UCSF). Currently, Dr. Bissell serves as Chief of the Gastroenterology Division at UCSF. As well as maintaining Bissell's Porphyria Research Program, Dr. Bissell is a leading expert in liver damage research, including cell-

based therapy and tissue remodeling for damaged livers. He is also a member of the Porphyria Research Consortium. His work for porphyria research dates back to his involvement in developing Panhematin for the treatment of the porphyrias. Panhematin was the first medication to be approved under the Orphan Drug Act of 1983. In addition to his having published over 100 articles, he has been on numerous boards and councils, including serving as President of the American Association for the Study of Liver Diseases (1998-2002). With his extensive knowledge of overlapping medical concerns, from liver damage to porphyria treatment, he is a valuable resource for our community. The APF also owes thanks to Dr. Bissell who is one of the experts training the next generation of porphyria experts via the *Protect the Future* program. We are fortunate to have Dr. Bissell as an integral figure of the APF.



Mary Schellenberger

had a recent experience that most porphyria patients do not have. She met with a porphyria specialist. Not many have this opportunity because there are not many porphyria experts in the country, which is why the APF has been supporting the training of young doctors as future experts. In her case, Mary was

fortunate to meet with renowned expert, Dr. Herbert Bonkovsky, whom she reported as not only a phenomenal doctor but a wonderful, compassionate man. She said that the whole team was great, too, and while she was there, she signed up for the porphyria research that is featured on the APF website section entitled, [Porphyria Registry](#). Mary also recently participated in the Awareness Week heightening awareness even at her son's motocross events. After the notice of her efforts and that of so many other APF members appeared in the newsletter, she copied the newsletter to send to her extended family and friends to further enhance porphyria awareness and asking for their help. *Even if it is \$5.00 it goes a long way. The foundation has saved my life, and I always remember to donate when I can.*

Mary is determined not to forget her part in increasing physician and patient education and awareness. Please Join Mary and make PORPHYRIA a household word!!!!!!!

Mira Geffner NORD Board Member



Did you know that the APF is a member of the National Organization for Rare Disorders (NORD)? As a member organization, we join other rare disease groups to combine our voices into a louder shout for attention to the needs of patients and families. NORD coordinates work among individual rare disease groups and unaffiliated patients and families, including sponsoring events like the American edition of Rare Disease Day on the last day of February every year. APF Director, Desiree Lyon Howe, served on the NORD Board of Directors for almost twenty years. Now I am honored to represent the APF at NORD. Back in the early 1980s, Desiree joined with other rare disease patient advocates to form NORD and testify before Congress in support of the Orphan Drug Act, a law that has encouraged FDA approval of 350+ treatments for rare diseases, including porphyria. Panhematin, the medication that I and many other acute porphyria patients rely on as the only specific treatment for porphyria, was the very first drug approved under the Orphan Drug Act.

It's almost too painful to look back and try to imagine what life was like for the family members who were diagnosed decades before I was. Acute Intermittent Porphyria (AIP) runs deep in my maternal grandfather's family. Some aunts and cousins were terribly ill and hospitalized for years before being diagnosed. Others were diagnosed ten years or more before effective treatment became available, and even though diagnosis saved their lives, their long-term health was severely weakened by AIP. The more time I spend with NORD, the more variations I hear on this same story: patients who go undiagnosed for years, often becoming progressively sicker as a result of the very care intended to heal them. It seems as if every rare disease group has at least one version of the "mystery diagnosis" problem to share. According to NORD: *"The rare disease patient community includes people afflicted with a wide range of serious and life-threatening disorders and syndromes. Their challenges are significant. Many are uninsured or under-insured. Some go years without the correct diagnosis, and most live day-to-day with concern about what the future may hold. Improving the services and effectiveness of rare disease patient organizations is an important way to begin alleviating the unique problems faced by these families."* That is why it's so important for the APF to participate in NORD and to serve as an active member organization. The American Porphyria Foundation needs strength in numbers to support treatment for the porphyrias and research for our cure. Working with NORD and its other member organizations can only make us stronger. — **Mira Geffner**

Vivian Evans was happy, healthy, and strong. A businesswoman with a love of the outdoors, she could be spotted hiking, at the beach, skiing, or coaching her daughter's sports. Then suddenly she started to develop mysterious symptoms: severe exhaustion, hearing loss, and sores developing on her hands that wouldn't go away. Doctors were confused, or unsure, of what was ailing Vivian and would send her on her way home after her multiple trips to the ER. The sores began to spread, affecting places like her back; finally, a hematologist recommended her to an infection specialist, whose diagnosis of Porphyria Cutanea Tarda (PCT) changed her life. After being referred to yet another hematologist, a new factor affecting her PCT was discovered: she had hemochromatosis, which is a genetic defect that allows for over-absorption of iron in the gastrointestinal tract, resulting in liver problems and other concerns.



When Vivian's ferritin levels (iron measurement) were tested, her levels were at 2,800; the normal range, according to NIH, is usually between 12-150 ng/mL for women. Because hemochromatosis is a more common genetic disease, affecting one in about 200, people with PCT are often afflicted with hemochromatosis. This is an important reminder of correlations between illnesses affecting similar systems. While Vivian may be on the mend, it's important to remember that while getting one's porphyrin levels checked, one should also have one's ferritin levels evaluated. Finally, it is also important to understand how other diseases can have a huge impact on a porphyria patient's health in general. We hope to hear more good news from Vivian Evans on her healing from this terrible ordeal!

Lyon's Share

THE APF IS YOU. YOU is anyone who has porphyria or has a family member or friend affected by it. We cannot operate the APF unless YOU help us fulfill our common mission to educate and enhance awareness among physicians and patients and to support research for better diagnosis and treatment. Where would we get money to operate, to maintain websites, education programs, and a host of other important services if it were not for YOU. Recently, I received a letter shaming me for us asking for donations. The caller was told she could be a member without any donation, but she said we should never ask people with porphyria since they were sick. Well, I am sick, too, but I don't feel that way. I feel all the more reason for us to work together to enhance porphyria awareness and education. I think you are like me and know that a foundation that is as active as the APF needs financial support. We are hard at work on YOUR behalf and ask that you help us help YOU and the thousands of people who contact us for assistance.

Your donations can take many avenues. YOU can honor someone, donate to the Protect the Future program to train young doctors as experts in the field, donate to support research or make a donation to help the staff purchase a new computer or pertinent computer program. Thank you in advance for understanding that I am happy to ask YOU to help support the APF. — **Desiree Lyon**

(PTF) Training Week



Dr. Karl Anderson will be hosting a **Protect the Future** training week for the new PTF doctors who were chosen to participate in our PTF program to train future porphyria experts. Members of our Scientific Advisory Board joined with the APF to initiate this important project so that the present expertise would not be lost. Young doctors, who are already well established in their fields of derma-

tology, hematology and hepatology, are selected to participate in the PTF program. Without these young physicians, we will have no one to develop new treatments, consult with primary care doctors and teach them about diagnosis and treatment, as well as write the medical textbooks, all of which the present experts have been accomplishing for thirty plus years.



Drs. Caballes, Yasuda, Wang, Mittal, Perini, Singal

It is our hope that you will see this important need and respond by helping us train these young doctors for the future. The training cost

for one doctor is \$80,000 and the following doctors are part of the PTF training, Drs. Wang, de Lima, Balwani, Liu, McGuire, Freilich, Guy, Singal, Narang, Caballes, Thapar, Singh, Perini, Lai, Lourenço, Parker, Abdel-Rahman, Rizk, Sood, Wickliffe, and Mittal. Their rich experiences and

fresh perspectives, combined with the PTF education and mentoring program, will make them innovators from the start of their porphyria expert specialty.

We cannot support such an outstanding and important program without YOU. We ask you to make a special donation to the APF and mark it **PROTECT THE FUTURE**.

Your Gift Is Essential To Train Young Experts.

San Francisco APF Member Meeting



APF member, Marlene Brezee, is shown enjoying the camaraderie at an APF Patient meeting. Another such meeting will be held on November 6, 2011 in San Francisco in conjunction with the American Association for the Study of Liver Disease (AASLD). Marquis Hotel, 55 Fourth Street, San Francisco, California in the Nob Hill A & B rooms from 1:00 p.m. to 5:00 p.m. with the doors opening at 12:30. Porphyria experts will be making presentations by Q & A sessions

and an opportunity to share your experiences with others receive support and encouragement and share our experiences with porphyria. This is an exciting opportunity to learn and help others learn. Remember, **Those who know the most — do the best**. If you are interested in attending, please contact Yvette at the APF via email: porphyrus@aol.com or call, toll free 1.866.APF.3635 to reserve a seat.

Sulfa vs Sulfur

Amino Acids and Essential Amino Acids by Dr Herbert Bonkovsky



There is much confusion on the internet about sulfa and sulfur. In fact, some acute patients are actually avoiding foods with sulfur unnecessarily.

Renowned expert, Dr. Herbert Bonkovsky, explains: Our normal diets contain proteins. In fact, regular and adequate intake of protein is essential to normal growth and health. Proteins are found in both

vegetable and animal sources of foods. The building blocks of proteins are called amino acids. Some of these amino acids, such as methionine and cysteine, contain sulfur. **Such amino acids are not the same thing as "sulfa drugs". They are not con-traindicated for patients with acute porphyria.** In fact, methionine is one of the **nine essential amino acids**: if adequate amounts of these nine amino acids [histidine, isoleucine, leucine, lysine, methionine, phenylalanine, threonine, tryptophan, and valine] are not consumed regularly, deficiencies will develop that can lead to malnutrition and disease. The reason is that humans are unable to make these amino acids and must take them in regularly, in order to achieve and maintain adequate levels to permit their bodies to make the hundreds of thousands of proteins that are essential for good health.

The Liver Meeting®

THE 62ND ANNUAL MEETING OF THE AMERICAN ASSOCIATION
FOR THE STUDY OF LIVER DISEASES 2011

San Francisco, CA • Moscone West • November 4-8, 2011



Medical Conventions & YOU



The APF will be exhibiting at the annual meetings of American Association for the Study of Liver Disease (AASLD) and the American Society of Hematology (ASH). We need volunteers, like Grace Warfield shown in the photo, to man the exhibit booths. The AASLD will be held in San Francisco from Nov 4-8, 2011 at the Moscone Convention Center. AASLD is the world's leading organization of scientists and healthcare professionals committed to preventing and curing liver disease. AASLD is the leading organization of scientists and healthcare professionals committed to preventing and curing liver disease. ASH will meet December 10-13, 2011 at the San Diego Convention Center. It is the world's largest professional society concerned with the causes and treatments of blood disorders. Volunteers for either convention booth can contact Yvette at the APF 1 866 APF 3635.

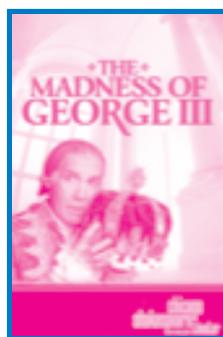
Agent Orange and PCT

The APF worked hard to make sure that porphyria cutanea tarda (PCT) was included as one of the 14 diseases and disorders presumed by the U.S. Veterans Administration to be the result of AGENT ORANGE exposure in "boots-on-the-ground" Vietnam veterans. Vietnam veterans who were exposed to Agent Orange, the toxic herbicide sprayed over the jungles between 1962 and 1971, now have increased rates of certain diseases and health disorders, including porphyria.

It would be easy for a doctor to overlook Agent Orange exposure as the cause of a patient's porphyria when other, more obvious risk factors are present. That's why it's so important to ask patients whether they ever served in the military when evaluating, diagnosing, and treating them. Approximately 20 million gallons of herbicides were used in Vietnam between 1962 and 1971 to remove unwanted plant life and leaves which otherwise provided cover for enemy forces during the Vietnam Conflict. Shortly following their military service in Vietnam, some veterans reported a variety of health problems and concerns which some of them attributed to exposure to Agent Orange or other herbicides. Porphyria Cutanea Tarda (PCT) is one of those diseases. The Department of Veterans Affairs has developed a comprehensive program to respond to these medical problems and concerns. The principal elements of this program include quality healthcare services, disability compensation for veterans with service-connected illnesses, scientific research and outreach and education.

More than 150,000 veterans are expected to submit Agent Orange claims in the next 12 to 18 months, many of whom are potentially eligible for retroactive disability payments based on past claims. For those of you who told the APF that you had tried to make a claim to no avail, please note that VA officials will review approximately 90,000 previously denied claims by Vietnam Veterans for service connection. See www.va.gov or call your local VA office to find out more information about your eligibility for PCT.

Media Campaign Pays Off



June 13th marked the last run of Alan Bennett's *The Madness of George III* at the Chicago Shakespeare Theater. This 1991 play, turned into the 1994 film ***The Madness of King George***, documents George III's struggle with mental illness while the Revolutionary War raged against Britain. Recently revised 20 years after its first run, this play showcases the unconventional and usually cruel methods of "curing" King George, who some physicians and historians now feel suffered from variegate porphyria. Combined with power struggles and a crumbling monarchy, his illness amplified the problems of war and a struggling royalty. The more coverage the porphyrias receive, the more likely this knowledge will infiltrate into mainstream culture. Maybe you have noticed porphyria references on television shows like "House, M.D." or "Scrubs." While these references are not always accurate, they serve as reminders to the public that a rare disease can exist and wreak havoc on people you may know and care about. We are proud that the APF has garnered more stories in TV series than any other rare disease organization. Remember, too, that YOUR stories in local coverage are great ways to heighten porphyria awareness, too. Many of our members have contacted their local media to encourage them to write or film a story about them. This has worked very well all over the country and has helped us help patients and them find the APF!!

RESEARCH IS THE KEY
TO YOUR CURE.

SUPPORT RESEARCH.

EPP Conference Calls And NYC Meeting



The APF also initiated two conference calls between the EPP patients in the trials and Clinuvel to update them on the FDA decisions. Dr. Phillippe Wolgen, CEO of Clinuvel joined in on one of the conference calls to answer questions and update the participants. While the results of the Clinuvel trial cannot be disclosed until the data has been analyzed, they noted

that from the success of Phase II, they will be pushing for a Phase III in the research in order to continue down the path of having Afamelanotide approved for EPP patients. On June 26th, members of the American Porphyria Foundation also assembled at the Helmsley Park Lane Hotel in New York City to discuss the recent EPP clinical trials. In attendance was APF Executive Director, Desiree Lyon Howe, porphyria specialist and Dean of Genetics and Genomic Sciences at Mount Sinai School of Medicine, Dr. Robert Desnick, and Daniela Schaefer, the Vice President of Business Development for Clinuvel, as well as a vibrant group of EPP patients and their families. Dr. Desnick kindly spent the afternoon with the group explaining in-depth EPP, the Consortium's research with Afamelanotide and the role of the FDA. In addition to exchanging pertinent information regarding the trial, the EPP families enjoyed meeting and communicate with one another; raising awareness and bringing together patients is the heart of the American Porphyria Foundation. Mat filmed a video of the meeting, which we hope to post on the APF website soon.

How the 340B Program Improvement Act Affects You

In July, a bill was introduced in Congress that if passed, could put at risk the availability of a number of treatments for rare diseases, including porphyria. This bill causes drug companies to sell treatments to hospitals for artificially low prices, regardless of the costs to manufacture and distribute. In some instances, orphan medicines, such as PANHEMATIN, will be sold for as little as **1¢**, despite the losses incurred to make it available. It also allows thousands of hospitals to purchase a rare disease drug for **1¢** and sell it to another hospital for a large profit. Worse yet, there are NO exemptions for rare disease drugs. You can imagine the manufacturer of PANHEMATIN would be hard pressed to make this complex treatment and sell it for **1¢**. This puts us in terrible jeopardy. This legislation could create a life threatening situation that involves YOU. The APF cannot educate Congress on the consequences of such legislation without your help. We must advise our Congressmen that expansions of 340B, no matter how well-intentioned, can have devastating consequences for patients who need orphan medicines, like PANHEMATIN. To help, contact the APF office toll free at: 866.APF.3635.



U.S. Food and Drug Administration
Protecting and Promoting *Your Health*

FDA News

Recently, The U.S. Food and Drug Administration (FDA) announced it is seeking input on its proposed oversight approach for certain mobile applications specific to medicine or health care called mobile medical applications ("apps") that are designed for use on smartphones and other mobile computing devices. This approach encourages the development of new apps, focuses only on a select group of applications and will not regulate the sale or general consumer use of smartphones or tablets. Today, mobile medical applications or "mobile medical apps," include a variety of functions, ranging from monitoring calorie intake, helping people maintain a healthy weight, and allowing doctors to view a patient's radiology images on their mobile communications device. According to Research2Guidance 2010, 500 million smartphone users worldwide will be using a health care application by 2015. The FDA is seeking public comments. To submit yours:

<http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm263332.htm> and to read about APPS for

<http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm263340.htm>



Dr. Tim Coté

From 2007 to May 2011, Dr. Coté served as Director of the FDA Office of Orphan Products Development (OOPD). That office is FDA's primary interface with companies seeking orphan designation for drug and device products or seeking guidance in navigating FDA processes in reviewing orphan products. As Director of OOPD,

Dr. Coté was one of FDA's most visible spokespeople on issues related to orphan product development and also served as one of the agency's chief liaisons with patient organizations. He recently became NORD's medical officer. His role at NORD will be to provide medical guidance in all areas — particularly advocacy and education — to promote fair, compassionate public policies; encourage the development of safe, effective treatments; and increase awareness of rare diseases and the needs of patients and their families.

We want to start a special closed FACEBOOK group for EPP people who are young adults. The name of the group will be

20° Below.

If you are interested helping facilitate this new group, please contact the APF.

Nutritional Advice for Porphyria

Nutritional Advice for Porphyria by renowned porphyria expert, Herbert Bonkovsky, MD and Jessy Philip, RD, PhD, Carolinas Health Care System, Charlotte, NC.



(The entire article, which is very comprehensive and includes menus and pertinent information, will be posted on the APF website.) Because over-nutrition and obesity are such a great problem in the USA and other western countries, it is important that patients with porphyria do their best to avoid becoming obese or gaining weight beyond their ideal body weights. The acute porphyrias [acute intermittent porphyria, hereditary coproporphyria, variegate porphyria, and ALAD deficiency porphyria] may be made worse by prolonged fasting or severe [‘crash’] dieting, because, in these forms of porphyria, glucose and other carbohydrates help to repress the activity of hepatic ALA synthase, the first enzyme of the heme synthetic pathway. In these forms of porphyria, uncontrolled up-regulation of ALA synthase in the liver is a necessary component of the metabolic abnormalities that may give rise to attacks.

The current general dietary recommendations for Americans, as developed by the Department of Health and Human Services and the Centers for Disease Control, <http://health.gov/dietaryguidelines/2010.asp>, should be followed by persons with porphyria, as well as those without. The keys are adherence to a varied and balanced diet with balanced, moderate consumption of carbohydrates, protein, and fats. To reduce the risks of cardiovascular diseases, such as atherosclerosis or heart attacks, the fats should include little or no trans-fats and preferably include a substantial proportion as unsaturated fatty acids [such as olive oil, safflower oil], rather than saturated fatty acids [such as animal fat]. The protein may be in the form of animal or vegetable protein. The carbohydrates should preferably not include large amounts of refined sugars or high fructose corn syrup, although oral or intravenous carbohydrate in the form of dextrose may be prescribed for therapy of acute attacks of porphyria. However, day in and day out, even persons with one of the acute porphyrias should not be consuming large amounts of dextrose (sugar) or fructose.

The treatment of an acute attack is focused on decreasing the up-regulation of hepatic ALAS1. This is done by the administration of sugar [dextrose] and by the administration of heme, which must be given intravenously. During acute attacks, patients often have nausea and vomiting, as well as disturbances of normal gastrointestinal function, so that it is necessary for the dextrose to be administered intravenously, as well. If the attacks are less severe, however, patients may be able to take in dextrose orally, such as by adding sugar to orange juice, by sucking on hard candies, etc. During such acute attacks, the usual therapeutic recommendations by experienced physicians are for the daily intake of dextrose or other metabolizable carbohydrates to be approximately 300 grams per day.

Certain drugs, such as barbiturates, phenobarbital, sulfonamides, and many others can precipitate an attack. Another factor that is capable of triggering acute porphyric attacks is excess intake of alcoholic beverages. Thus, persons with acute porphyria should avoid any binge drinking. **Good general advice is that men should drink alcohol either not at all or not more than two drinks per day and women should drink not at all or not more than one drink of alcohol per day.**

There is no convincing clinical or scientific evidence that any particular foods (with the exception of alcoholic beverages, as described above) are capable of triggering or worsening acute porphyric attacks. There are, however, some foods that have been shown to contain chemical substances that, in large amounts, can up-regulate hepatic ALA synthase. Such foods include charcoal-broiled meats, cabbage, and brussels sprouts. The amounts of such foods that would need to be eaten in order to produce induction of hepatic ALA synthase are probably far above the amounts that would be eaten as part of reasonable, well balanced diets. None of these foods needs to be avoided completely by persons with acute porphyria, unless they have true allergies to them, which are very uncommon. **Moderation in all things is the best course of action.** The APF website lists suggested meal plans for persons with acute porphyria who are of normal weight and with normal daily needs for energy [~30-35 Kcal/kg BW/d].

Dieting in Acute Porphyria. It is important that persons with acute porphyria avoid crash diets with extreme decreases in daily carbohydrate and caloric intakes. However, it is also important that they avoid obesity. If they already are obese, they should gradually lose weight. This should be done with a formal diet plan and under the supervision of an experienced physician and nutritionist.

NEXT NEWSLETTER

SEE NUTRITIONAL ADVICE FOR EPP, PCT, CEP AND HEP OR
READ ALL NEW DIET INFORMATION SOON ON THE APF WEBSITE

WWW.PORPHYRIAFOUNDATION.COM

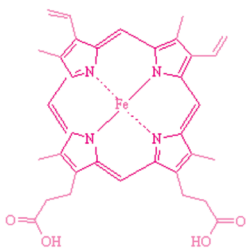
Conference on Rare Disease And Orphan Products



The first Conference on Rare Disease and Orphan Products will be held October 11-13, 2011 in Washington, DC is supported by the Drug Information Association, Duke Department of Pediatrics, FDA and NORD. Join in the unique opportunity for all who are focused on rare diseases to gain a common understanding of the previous and emerging challenges and opportunities and strategies for the future. One of the keynote speakers is Dr. Francis Collins who is Director of the National Institutes of Health (NIH) and noted for his landmark discoveries of disease genes and his leadership of the Human Genome Project

(HGP). His book, *The Language of God: A Scientist Presents Evidence for Belief*, has been a national best seller and an inspiration for people who have questions about the spiritual and intellectual issues of the human genome. Collins is a member of the USA Science & Engineering Festival's Nifty Fifty, a collection of the most influential scientists and engineers in the United States that are dedicated to reinvigorating the interest of young people in science and engineering.

Dr. Collins has been a major supporter of rare disease therapies and says, "If you or your family were affected, it wouldn't be rare for you. And the study of rare diseases has taught us more than most people realize. Furthermore, the opportunities to capitalize on what we have learned so far have never been greater. If you care at all about biology and about understanding medicine, rare diseases are critical."



**Are you a woman
at least 45 years of
age with
Acute Intermittent
Porphyria (AIP)?**

If so, we would like to invite you to participate in a 24 hour observational study to investigate the Molecular basis of sleep in people with AIP. You may also invite your female

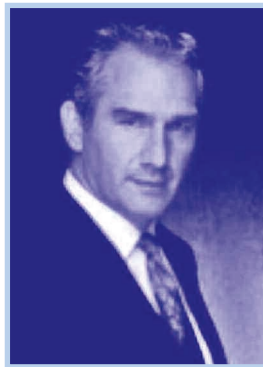
friends of similar age without porphyria to be part of the control group.

You will receive \$300.00 for taking part in and completing the study. If interested, please contact Gale Groseclose at 704-355-4875 (email: gale.groseclose@carolinashealthcare.org) or contact Dr. Ryan Caballes at ryan.caballes@carolinashealthcare.org

ELIGIBILITY CRITERIA INCLUDE:

- *ABSENCE OF MENSES FOR AT LEAST A YEAR
- *NOT USING ORAL CONTRACEPTIVES OR HORMONE REPLACEMENT THERAPY (HRT)
- *HAVE NOT RECEIVED BLOOD TRANSFUSION PRIOR TO 6 MONTHS OF ENROLLING
- *NOT CONSISTENTLY ON IBUPROFEN, BETA-BLOCKERS, ALPHA-BLOCKERS, AND NICOTINE PRODUCTS
- *HAVE NOT TRAVELLED TO ANOTHER TIME ZONE WITHIN 2 MONTHS OF EXPECTED PARTICIPATION
- *NOT HAVE HISTORY OF ALCOHOL ABUSE

In Memory



Anthony Herrera, who played the villain James Stenbeck on the long running soap opera, *As the World Turns*, died recently. He was a strong advocate for the APF when Desiree helped facilitate his becoming a patient at MD Anderson Cancer Center after his diagnosis with a rare form of cancer. At his recovery, she encouraged him to become a cancer advocate. He not only en-

hanced cancer awareness, he also encouraged doctors to learn about porphyria.

We also are saddened to hear of the passing of other dear friends whose loved ones have chosen to honor their lives by making a memorial gift to the APF. We sincerely appreciate their thoughtfulness and desire to help others with the disease. Please join us in thanking:

Edward T. Hanus, Jean and Gordon Lane, Martin T. Franke, Marti and Dale Streitenberger, Magda Dimmendaal, Lynn M. Schott, Victoria and Gary Jasiak, Cindy and Keith Streitenberger, Sandra and Patrick Schuette, David Schuette, Claudia J. Sundberg, John and Naoma Schmidt, Hartford Square Condo for **Patricia Brass-Bandekow**; Mary Puccia for **Dean Puccia**; Leroy Olsak for **Geneva Burk**; Mary E. Alfrey for **Terry Denise Legge**; Patti de Groot for **Alberta Bolks**; James Bain for **Laurie E. Breiner**; Vincent Shell for **Dorothy Shell**; Gary R. Horn for **Sandra Horn**; Mary Carriker, Arleta and Ralph Seery, Joan and Chester Purkey, Jr., Barbara and Robert Fizer, Shirley and Robert Coykendall, Diane and Bill Park, Pam Carriker, Peggy Rosenbluth, Bruce Carriker, Bill and Mary Ann Ree, Ron and Lou Rollins Mary E. Carriker, Ralph and Arleta Seery, Joan and Chester Purkey, Jr., Barbara and Robert Fizer, Shirley and Robert Coykendall, Patricia and Roy Julius, Winona and Junior Pruitt, Beatrice and Robert Darmon, Brenda and Robert Ferguson for **Bill Carriker** and Donald Johnson for **Peggy Lewis Johnson**.

In Honor

We thank the following people for honoring their family and friends with a gift to the APF:

Mary Puccia for **Mary Hargett**; Philip Weismehl for **Jessica Melton**; Eric S. Gray for **Ralph Gray**; Suzanne C. Schellenberger for **Mary Schellenberger**; Jennifer R. Ewing for **Desiree Lyon**.



The information contained on the American Porphyria Foundation (APF) Web site or in the APF newsletter is provided for your general information only.

The APF does not give medical advice or engage in the practice of medicine. The APF under no circumstances recommends particular treatments for specific individuals, and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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What's New at the APF www.porphyrifoundation.com

Updated Member Stories Section: Our members enjoy reading the experiences of other people with porphyria. If you are interested in having your story in the newsletter or on the website, please contact Desiree at the APF. She will write it for you if you do not want to do the writing.

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

The Emergency Room Kits have been updated and expanded. This is the best money you have ever spent. Also purchase an APF DVD, *Porphyria Live*, and get one free for your doctor.

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