



Erythropoietic Protoporphyrin (EPP) Clinical Trials — 83 Research Volunteers

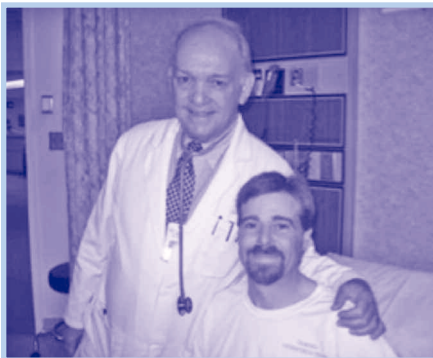
APF members throughout the country have volunteered as research patients for the EPP clinical trials with afamelanotide, now named SCENESSE®. The successful results of the European Phase III trials with SCENESSE® were announced recently and confirmatory European Phase III EPP trials are due to commence soon. Patient volunteers for the USA trials are traveling to the following six sites overseen by porphyria experts: Dr. Karl Anderson, University of Texas Medical Branch, Galveston; Dr. Montgomery Bissell, University of California, San Francisco; Dr. Joseph Bloomer, University of Alabama, Birmingham; Dr. Herbert Bonkovsky, Carolinas Healthcare Center, Charlotte; Dr. Robert Desnick, Mount Sinai School of Medicine, New York City; and Dr. James Kushner, University of Utah, Salt Lake City.

We sincerely thank the EPP research volunteers for sacrificing their time and energy for the benefit of all people with EPP! Their hours are long, the travel is hard, the waiting time is tiring and the effort is difficult. They all deserve our appreciation. The stories below are only two of the many heartwarming EPP trial stories.

Martha Atkins volunteers at age 95: Recently, APF member, Martha Atkins contacted the office to volunteer for the EPP clinical trials at the University of Texas Medical Branch in Galveston, Texas. After Martha answered the obligatory questionnaire, the APF coordinator, Elizabeth Pettit, posed the final question, "All we need now is your birthdate." To her surprise, Martha told her that she was 95 and was born in 1915. Knowing Desiree would want to hear Martha's story, she handed her the telephone. Desiree found Martha to be a delightful woman and commented that the porphyria community would enjoy hearing about Martha's willingness to take on such a strenuous undertaking as the EPP trials at age **95!!!** Next Desiree asked what motivated Martha to volunteer as a research patient. Prior to her retirement, she said, she had managed a medical clinic and felt advancing medicine was the way to help people now and in the future.

Martha, is an extraordinary person. She volunteers as the bookkeeper for her church in Corpus Christi. She loves to garden and tends her own large vegetable and flower garden by herself. Although she was not able to participate in the EPP clinical trials due to the flight schedules, she will participate in the upcoming longitudinal studies. Martha exhibited the kind of spirit we all should have, namely, a love of her fellow man, a love of adventure and willingness to help others.

Rob Saupe's family surprise: When Rob Saupe was a baby, his mother brought him outside in the sun while she hung up clothes.



After a short time, he started screaming. For years, he was tested for allergies, including grass, pollen, soap and various foods. When Rob was five years old, his mother took him to see a doctor who had just completed an internship under porphyria expert, Dr. James Kushner. The doctor looked at Robert's hands and face and promptly told them to make an appointment with Dr. Kushner, who, in turn, diagnosed him with (EPP). (Photos: Left, Dr. Kushner and Rob; Right, receiving the implant)

When he heard about the EPP trials, Rob volunteered. Not knowing which of the sites would be assigned to him, Robert was thrilled to learn he would once again see Dr. Kushner in Salt Lake City. There was also another very poignant reason he was happy about the location of the site. He had only recently reconnected with his 22 year old twins, who live in Salt Lake City and had been saving for a trip to see them. Robert tells us that years ago he was not an upstanding man, but after a conversion experience, his life changed and his children became very important to him.

The trials gave them the opportunity to meet for the first time in many years. Rob now talks to his children every day and enjoys hearing them say, "Love you, Dad;" proof, he says, that God does, indeed, "work in mysterious ways." Rob has begun the trials and is pleased with the progress, especially since now he does not have to be covered when he ventures outside. When a bystander saw Robert covered up like a thief at a NASCAR race, he asked if Robert had robbed a 7-11 to which Robert replied: "Shh, I'm in hiding," but he doesn't have to hide any more.

Progress Report: Porphyrias Research Network (RDCRN)

We are pleased to announce that the Porphyrias Consortium of the Rare Diseases Clinical Research Network (RDCRN) has made significant progress during the first eight months of their inaugural year. If you will remember, the Consortium won a \$4.2 million grant to improve diagnosis, treatment, and quality of life of porphyria patients. The RDCRN includes five regional sites, each overseen by a porphyria expert, who is the Principal Investigator, as well as a *Protect the Future* physician-trainee, namely, The Mount Sinai School of Medicine (R.J. Desnick, PhD, MD), University of California at San Francisco (D.M. Bissel, MD), University of Texas Medical Branch at Galveston (K.E. Anderson, MD), University of Utah (J.P. Kushner, MD), and University of Alabama at Birmingham (J.R. Bloomer, MD) and Desiree Lyon Howe, Executive Director of the American Porphyria Foundation. The PTF doctors include Drs. Ashwani Singal, Bruce Wang, Brenden McGuire, Marisha Balwani, Lawrence Lui, and John Phillip. Important to the RDCRN are the coordinators who help facilitate the projects.

The Consortium has met four times and held monthly conference calls. In a short period of time, they accomplished the following:

- development of the website and its content, <http://rarediseasesnetwork.epi.usf.edu/porphyrias/index.htm>;
- development and NIH approval of their Longitudinal Study, which is the first and most important project;
- recruitment of faculty trainees;
- development of The Porphyrias Repository;
- coordination of their biochemical and molecular porphyria diagnostic laboratories so that each patient and sample is diagnostically confirmed and the specific causative mutation identified; and
- coordination of all efforts and activities with the APF.

Porphyria Registry

The new Porphyria Registry is a means for patients to be contacted about clinical research opportunities and progress. It is anonymous and free of charge. All data will be stored in a secure, computerized database. No personal identifying information will be given to anyone without your approval. Over 100 patients have already registered via the **Porphyria Registry** found on the APF website: www.porphyriafoundation.com.

Please follow the instructions carefully.

At present, the researchers need AIP patients with frequent attacks. There are a number of research groups, so be sure to look for the Porphyria Consortium and register with that group.

Swim Team Donates \$1000



If you know how to swim and are age 18 or over, you can join the RESTON MASTERS SWIM TEAM based in Reston, Virginia. Recently, the Jim McDonald Lake Swim, which is an event to honor the founder who died of lymphoma, gave the APF \$1000. Over the past 23 years, the event has grown and has become a national event, which supports a variety of foundations, including the APF. Such venues are a major means to promote porphyria awareness and educational programs. *Thank You RESTON MASTERS SWIM TEAM and APF member, Mike Kenworthy.*

Like Mike, you, too, can host a fundraising event to help fund the many services of the APF. We will send you materials for your event, as well as other supplies, to make your event a great success!!!!

Gabby Honored



The APF has named the EPP trials in memory of Gabby Cochrane, whose mother, Lesley, wrote a poignant memoir of her child's life and struggle with EPP. The chronicle of Gabby's life and her mother's angst over Gabby's plight is a moving testimony of a child's courage and a mother's unending love.

Gabby, who was extremely photosensitive, had a short but significant life. Everyone who knew her was touched by her joyous spirit and bravery, which is reflected in the photo of Gabby at her school race. Despite the

bandages, sun protective gear and heavy sun blocks, Gabby ran with the heart of a champion.

For Gabby and children like her who suffer from EPP, we thank the participants in the EPP trials.

YOU ARE THE APF –THE APF IS YOU!



Two Daughters with AIP Mothers

Haley Eubanks: Growing up, I've always had the fear of losing my mom, Karen. She's the strongest person I know and what makes her so strong is the will power and strength God gave her. My mom has a rare disease called acute intermittent porphyria (AIP). Although there's no cure, there is a treatment called Panhematin that my mom receives every week through a port. This medicine, which she receives every 21 days, controls her attacks.

When I was in kindergarten, my mom quit her job. She explained that she was sick and not able to work anymore. Since I was five years old, I didn't quite understand, particularly as the sickness never left and she was hospitalized a lot. I was attached to my mom, so her not being there felt like a part of me was lost. I only went to the hospital twice because my family did not want to startle me. One time she was in for over three months and as a child I told people it felt like it was forever. But sadly, she returned to the ICU.

When I visited her, she didn't know who I was. She couldn't talk and she looked like she was already dead. The condition she was in was unbearable for me and thinking about the pain she went through made my pain increase. School was supposed to be my escape but it made things worse. My body felt like shutting down, too. I couldn't close my eyes at night because I was afraid I would see her die in my dreams. I felt like there was no purpose in life if my mom passed. My dad felt the same way. Thank God, the Panhematin treatment worked and my mom returned home. It felt like the day of redemption and a weight had been lifted off my whole body. In a week, she had returned to her normal self again.



Chelsea Kanskar: Since she was a young girl, Chelsea helped her mother, Lisa, promote porphyria education and awareness in their Michigan community, as well as host fundraising activities for the APF. Reminiscing about her many endeavors, Chelsea told us that the teachers and administrators were always supportive of the family's fundraising efforts, even buying gifts and stopping to chat at each event. Starting in the eighth grade, Chelsea asked each classroom to donate cans and gave prizes to those who raised the most money, including passes to a local country club, a pizza party, and flowers for the class teacher. When she started high school, the family's fundraiser encompassed selling purple cotton candy thus promoting porphyria, whose name comes from the Greek word *porphyrus*, meaning purple. This year, she and her family raised hundreds of dollars for the APF through a Valentine's Day carnation sale and by selling bracelets marked with the APF website address. This fall, Chelsea enters college to study microbiology. Her scientific career choice and years of involvement in supporting the APF is an outcome of growing up often seeing her mother, grandmother and uncle sick and suffering terrible pain. "I thank God I can fundraise and enhance education and awareness of the porphyrias for the APF. He makes it all possible.

Plants and Porphyrin



Porphyryns turn light into life. Plants need them for photosynthesis. Animals, including humans, use them for transporting oxygen in their blood. But excess porphyrin is harmful. Now USDA scientists, working with medical researchers at Dartmouth, have discovered how some green plants may regulate these life-giving chemicals—a finding that could someday protect crops or people. The scientists found a natural plant enzyme which deactivates porphyryns in plants and animals. The concept came from cooperative research between Dartmouth Medical School and a natural products research unit at the University of Mississippi in Oxford.

In green plants, chlorophylls, which are derived from porphyrins, trap solar energy and turn it into food. Some herbicides prevent

chlorophyll synthesis and cause porphyryns to accumulate to abnormally high levels. Plants then become hypersensitive to light and die. This works well for killing weeds, but since the herbicide is applied when crops are in the field they, too, could be injured. Crops could be bred, or genetically engineered, to enhance their levels of the enzyme that deactivates the porphyryns. This would protect the crops when the herbicide is applied.

This discovery in plants may also lead to new ways of preventing or controlling human porphyria. Cells of people with porphyria don't properly convert porphyryns into heme, which is the deep-red, iron-rich component of hemoglobin. Porphyrin buildup can cause nerve malfunction, resulting in weakness, nausea and skin rash; and gives urine a port-wine color. In all porphyrias except AIP, people are hypersensitive to light.

Beautiful Newport, Rhode Island



was the scene of the 2010 Gordon Research Conference (GRC) on **The Biology and Chemistry of Tetrapyroles** attended by members of the **APF**

Scientific Advisory Board of Porphyria Experts and Protect the Future doctors.

These GRCs provide an international forum for the presentation and discussion of frontier research in the biological, chemical, and physical sciences, and their related technologies. For over 75 years, GRC's high-quality meetings have been recognized as the world's premier scientific conferences, where leading investigators from around the globe discuss their latest work and future challenges in a uniquely casual, interactive format. The GRC is also committed to bringing young scientists together to discuss their current research and build informal networks with their peers



that may lead to a lifetime of collaboration and scientific achievement. Scientists with common professional interests, like porphyria, come together for a full week of intense discussion and examination of the most advanced aspects of their field.

As with all Gordon Research Conferences, this one provided ample opportunities for informal interactions in the afternoons and evenings, while the Poster sessions provided a venue for graduate students and post-docs to discuss their research with leaders in the field. The meeting was held at the lovely Salve Regina University which is situated on the beautiful Cliff Walk in Newport.

The Research Consortium used this time to meet, as well.



Lyon's Share: Your Story's Impact

After years of heading the APF, I have found that patients can often learn more about their illness through stories about real people than medical text. Real stories make the disease more palatable; they give hope and present challenges that others have overcome, all of which enlarges the readers capacity to do the same. In fact, from the inception of the APF, we have made our members' stories a major part of our educational program, not just to help people cope psychologically, but to help them learn complex medical information. Your stories are easier to read, they are more memorable; and they generally have more success in guiding people to take directed action than to read it in a textbook or on a web page. Knowing that, I hope that more of you will send us your experiences to publish in the newsletter and on the website. If you don't like to write, just email me at lyonapf@aol.com and a writer will capture your experience. There is power in your story! Please share it!!!

My book, **Porphyria, A Lyon's Share of Trouble**, details my own porphyria journey, as well as many of the remarkable stories that people have shared with me over many years. Read the heartwarming, funny, sad, courageous and outrageous stories, like the American Indian who had a secret to hide, the balloon race, the CEP patient who missed being touched, the woman who unearthed the royals' graves, and many more that will keep you captivated. To order the book, please contact the APF. **ALL** proceeds are donated to the APF patient and physician educational programs. — **Desiree Lyon Howe**

Projects You Can Support

The APF is YOU. The projects and services we provide are for people who have porphyria. The following are a few projects you can support with your donations.

Physician Education is extremely important to our health. Most doctors have never heard of porphyria and don't know how to diagnose or treat it without information from the APF and the experts who write the publications and medical texts. The experts also consult with doctors around the country on testing and treatment. The APF also sends info to your doctors and keeps them abreast of the new developments, as well as exhibits at significant medical meetings.

Patient Education is essential to improve your health, as knowledge is power.

Research is absolutely key to improved diagnosis, treatment and a cure. Your donations can go specifically to our research programs.

Protect the Future (PTF) program trains young doctors with present experts so that we will be assured of having a future generation of porphyria experts, clinicians and researchers. Far more PTF doctors are needed.

In Honor and **In Memory** is a means to honor your loved ones with a gift to the APF.

Facebook, Twitter and You



APF has expanded its social networking program by adding Facebook and Twitter and enhancing our bi-monthly internet Enews. Within a week, Facebook grew to several hundred members and is growing every day. The value of social networking cannot be measured. For instance, some people with EPP read about the EPP trials for the first time on Facebook and promptly contacted the APF to learn how they might volunteer to be a research patient. After volunteering, some of them have been extremely helpful to the others by sharing their research experience with the others in the group, which is very interesting reading, especially when they compare their "tans."

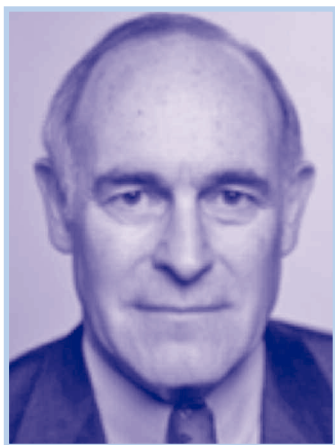
When you join the APF Facebook group, you will have the opportunity to communicate with other people with porphyria, as well as receive announcements of other research trials, events, and updates.

If you have not been to the APF Facebook group, please join us. Your comments and questions are very important to all of our members.

Some of the topics thus far are:

- securing a diagnosis,
- taking Panhematin,
- finding a doctor,
- the EPP trials,
- photosensitivity and photoprotection,
- cancer treatment and porphyria
- and many other important subjects

Watch the APF **Twitter**, too, which is updated often.



Desnick New Dean

Porphyria expert, Robert Desnick MD, PhD, was recently appointed Dean for Genetics and Genomics at Mount Sinai School of Medicine. Under his leadership, Mount Sinai will continue to advance basic and clinical research and facilitate translation of new discoveries into diagnostics and therapeutics. Dr. Desnick has played a pivotal role in the development and advancement of genetic research programs, including the porphyrias.

Dr. Desnick has been a member of the APF Scientific Advisory Board for over two decades and is Co-Chairman of the Porphyria Research Consortium. Dr. Desnick also heads the Porphyria Center and DNA Laboratory. He is a Professor of Genetics and Genomic Sciences, Obstetrics, Gynecology and Reproductive Science, Pediatrics, Gene and Cell Medicine, and Oncological Sciences.



International Conference on Rare Diseases & Orphan Drugs

Tokyo, Japan will be the location of another important conference, the **7th Annual International Congress of Rare Diseases and Orphan Drugs (ICORD)** on May 21-23, 2011. The ICORD mission is to improve the welfare of patients with rare diseases and their families world-wide through better

knowledge, research, care, information, education and awareness. ICORD is an International Society for all individuals active in rare diseases and/or orphan drugs.

The VII ICORD Conference will offer a platform for the exchange of perspectives for medical and healthcare professionals, patients and patients' groups, basic and clinical researchers, policy-makers, government officers and pharmaceutical, biotechnology and medical device industries. Topics of discussion will include: Research, Diagnosis, Treatment, Orphan drugs, Health policies on rare diseases and orphan drugs globally, ethical issues and social aspects of rare diseases, international networking, and Patients' needs. See www.ICOD.com.

Sulfa Does Not = Sulfur

Thanks to the educational efforts of the APF, many patients, families and physicians know that certain drugs are very dangerous in acute porphyrias. Sulfonamide antibiotics are among the best known drugs that are unsafe in acute porphyria. (It's not clear that other sulfonamide drugs are porphyria triggers, sulfonamide antibiotics are particularly unsafe.) Although doctors don't really know why sulfonamide antibiotics are harmful to people with acute porphyria, they are classic culprits in drug-induced porphyria attacks, and it is easy to avoid them by using safe alternatives. It is important not to confuse sulfonamide (or sulfa) drugs with sulfur. Sulfonamides are man-made substances, and although they contain sulfur, they are complex compounds and behave entirely differently in the body. Sulfur is a naturally occurring chemical element and an essential nutrient that is present in a wide variety of foods and in varying quantities in plants.

The danger of sulfa drugs in acute porphyria arises from the way humans metabolize (or process) these medications and is completely unrelated to the presence of sulfur. A sulfonamide chemical or drug consists, in part, of a sulfur atom linked to a nitrogen atom. But not all chemicals containing sulfur atoms are harmful in porphyria, and sometimes not even if there are sulfur atoms linked to nitrogen atoms. It depends on the properties of the whole drug or chemical molecule. If you have questions about drugs or foods it's best to speak with your doctor about them.

See the
Safe/Unsafe Drug Database for Acute Porphyria
and
**Emergency Room Guidelines
for Acute Porphyrias**
on the APF website Home Page: www.porphryiafoundation.com

Testing Not in Attack

Many of the calls we receive at the APF relate to diagnosis and the most asked question is, "Can testing be done when a person is not in an attack?" The answer is, "YES." However, it is important for the patient and the laboratory and the doctor to make sure that the correct tests are ordered, the lab is qualified to perform the tests and the doctor can interpret them correctly.

One laboratory that performs these diagnostic tests is at the University of Texas Porphyria Center and Laboratory in Galveston, Texas under the leadership of Dr. Chul Lee. DNA testing is performed at Mount Sinai School of Medicine in New York City. If you are having difficulty with testing issues, please contact the APF for assistance.

Doctor, Listen to Me



Thom Schillinger used an excellent tactic to gain his doctor's attention to his multiple porphyria symptoms and the need for appropriate testing, particularly since he only had a few minutes to do so. Thom wrote his main symptoms on a list, which he handed to the doctor before he detailed them to the doctor during his visit. This made it easier for the doctor to focus on the symptoms.

Providing a similar list when you go to the emergency room (ER) is also very helpful. Remember that the APF has a very comprehensive ER/Primary Care Physician Kit for purchase. The kit is a large notebook filled with physician information on diagnosis and treatment, testing, and a host of other pertinent data, which has been written by porphyria experts.

APF member Kathy M. notes, "After many trips to the ER and many different doctors who didn't know anything about porphyria, I decided to order an ER Kit. I was surprised at the large amount of information it contained. It had my name on the front which immediately caught the attention of the medical staff. When I showed the ER team my new ER Kit, the doctors and nurses paid close attention to it and TO ME. Every person with an acute porphyria would benefit greatly from having an ER kit."



Upcoming Newsletter: Food and Porphyria

Many of our members have questions about food and diet and porphyria.

Watch the next newsletter for an in depth article on the glucose effect on diet.

Learn about misinformation about certain foods causing attacks.



Porphyria Live, DVD Buy One, Get One for Your Doctor FREE

If you don't own a copy of the APF's **Porphyria Live** DVD, and you want to learn more about all types of porphyria and meet the experts in their laboratories and clinics, you have the opportunity to purchase a copy for yourself and get a copy for your doctor FREE. The award winning DVD was professionally produced at Porphyria Centers of Excellence at Mount Sinai Medical School in New York City and at the University of Texas Medical Branch in Galveston, Texas. Renowned porphyria experts, Dr. Sylvia Bottomly, Dr. Karl Anderson and Dr. Robert Desnick gave outstanding presentations on each of the porphyrias, focusing on diagnosis, treatment, research and other pertinent information. The viewer is given a trip through porphyria laboratories, clinics and treatment centers.

A particularly valuable scene was with patient, Karen Eubanks, who not only described her experience with acute intermittent porphyria (AIP) but also allowed the cameras to capture her at the UTMB Porphyria Center taking her Panhematin infusion. Karen's husband shares a poignant description of his wife's illness, as well as a helpful insight as a caretaker. The viewer is introduced to Ann Warnke who is outfitted in her sun protective gear to keep from the painful burning that can occur with EPP. Another patient shows the viewers his PCT damaged skin and talks about his upcoming treatment. Other patients and family members provide exceptionally interesting perspective on life with the porphyrias.

You can purchase the Porphyria Live DVD from the APF and remember, if you purchase a DVD, we will send one to your doctor for free. Be sure to include the doctor's contact information. Don't miss this outstanding opportunity to enhance your and your doctor's knowledge.

In Memory

We are saddened to hear of the passing of dear friends. Some of their loved ones have chosen to honor a life by making a gift to the APF. We sincerely appreciate their desire to help others with the disease. Please join us in thanking: Dr. and Mrs. Chao and Staff, Denise and Rudolf Pillmeier for *Vincent K. Farina*; Louise H. Davis for *Denise Byrd*; Ralph Gray for *Fred L. Gray*; Carolyn W. Hall for *Wendell Hall*; Theresa A Brett, The Ryzner Family for *Douglas J. Brewer*.

In Honor

Friends of APF members have also chosen to honor people who are very special to them through their gifts to the APF. We sincerely thank: Carolyn W. Hall for *Gaylord Hall*; Eric S. Gray for *Ralph Gray*.



CEP Families

The APF is initiating a special CEP FAMILY IN TOUCH network. Congenital Erythropoietic Porphyria or CEP is the rarest porphyria with less than 200 cases worldwide. It is also the most photosensitive and difficult porphyria to manage. Since it is so rare,

we would like to help connect CEP families with each other.

For an interesting, heartrending and informative view of CEP, please see Nicole Brooks blog about CEP, her daughter, Aubrey, and the unique challenges of a CEP family. When Aubrey was born in 2008, she was a healthy child, however, a few weeks after she was born, the first sign of illness appeared when her parents, Nicole and Doug, saw reddish-orange urine in her diapers. The doctors told them not to be concerned until she had pneumonia and anemia and the nurses noted her urine. When Aubrey began blistering and scabbing, another series of misdiagnosis began. For the rest of the story, read Nicole's wonderful blog, www.aubreybrooks.com.

If you are a member of a CEP family and would like to participate, please contact anniepanglepf@aol.com.

Medical Conventions

Volunteers are needed to help man the APF exhibit booth at two major medical conventions:

The American Association for the Study of Liver Disease (AASLD) to be held in Boston, Massachusetts at the Haynes Convention Center October 29–November 2, 2010. The Liver Meeting® is the premier event in the science and practice of hepatology. AASLD is designed for physicians, surgeons, scientists, educators, nurses, physician assistants, and all other hepatology health professionals. With approximately 9,000 attendees, this is the world's largest liver disease convention.

The American Society of Hematology (ASH) will be held in Orlando, Florida on December 4-7, 2010 at the Orange County Convention Center. ASH is the world's largest professional society concerned with the causes and treatments of blood disorders. The mission of the Society is to further the understanding, diagnosis, treatment, and prevention of disorders affecting the blood, bone marrow, and the immunologic, hemostatic and vascular systems, by promoting research, clinical care, education, training, and advocacy in hematology.

Both meetings are very important to promote porphyria awareness and education for physicians in the fields of hepatology and hematology. If you live in the Boston or Orlando area and can help us at the exhibit booth, please contact the APF. We ask that you assist us by manning the booth for half a day, handing out educational materials to doctors and discussing your case with them. To participate, please contact Annie Pangle at the APF, **1.866.APF.3635**.

APF and the Media



APF member, Irina Jacobs, is one of many patients who were diagnosed after viewing one of the TV programs secured by the APF. Below Irina relates her journey to diagnosis.

I was born in Ukraine and remember my first symptoms of erythropoietic protoporphyria (EPP) at age four. After spending a day outside, my hands began itch and felt on fire, but there were no visible signs. Throughout my childhood, I received every "diagnosis" from allergies to jellyfish stings.

When I was 20, I spent a day in the sun and woke up with swollen hands, a swollen face and my eyes swollen shut. Doctors gave me anti-inflammatory medication but not a diagnosis. However, a few years later, I saw an episode of *Mystery Diagnosis* on the Discovery Health Channel featuring Craig Leppert, who had EPP. Craig's symptoms were identical to mine—they could have written that episode about me. I brought the doctor a picture of my swollen face, a printout of an article about EPP and asked him to test me for it. The test came back positive for EPP.

I am now 26 and am happily employed indoors as an attorney. I buy protective clothing and cover up as much as possible. Driving is the hardest part. I wear white gloves, which help my hurting hands tremendously. I am very thankful to the American Porphyria Foundation and to Craig Leppert for helping me find a diagnosis.

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Television Coverage

Every year, the APF engages in campaign to gain media attention to porphyria. We have been more successful than any other rare disease foundation and have had more television attention than even many common diseases. Our aim is not only to enhance porphyria awareness, but also to help people, like Irina Jacobs, get diagnosed with porphyria. The following is a partial list of television programs to illustrate our success:

Mystery Diagnosis

ER

Castle

Dr. Oz

Anderson Cooper 360

Discovery Health

Fox News

CNN Documentary

National Geographic

House

Gray's Anatomy

Medical Mysteries

Dr. Sanja Guptha

CNN News

Montel Williams

ABC News

Travel Channel

Scrubs



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

Doctors are Recruiting Patients Now for clinical research studies. The experts are seeking research volunteers for a project that involves people with AIP who have frequent attacks. If you would like to participate, please contact the APF. We will then put you in contact with the experts near you. It is best to have documentation of your porphyria.

National Registry: Remember that the Porphyria Registry is on the APF website. This registry is private to the experts and will be used to help determine incidence and locate research volunteers. To register and be counted as a porphyria patient, please see the Porphyria Registry on the APF website: www.porphyrifoundation.com.

See the **Safe/Unsafe Drug Database for Acute Porphyria** and **Emergency Room Guidelines for Acute Porphyrias** on the APF website Home Page.

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