



Porphyryns and Porphyrias in Stockholm

Physicians and scientists specializing in porphyrias and related disorders came together from all over the world in Stockholm in June to exchange information and learn from colleagues. Attendees from the U.S. included APF Scientific Advisory Board members. With your support, *Protect the Future* program participants attended as well.



(See article, page 3.) From left: Dr. Robert Desnick, PhD, MD, Dr. Lawrence Liu, MD, Dr. Chul Lee, PhD, Dr. Karl Anderson, MD, Prof. Rafael Enriquez de Salamanca, MD, Dr. Manish Thapar, MD.

• • • • • EPP Treatment News • • • • •

At the end of July, APF members and families dealing with Erythropoietic Protoporphyrria (EPP) had the extraordinary opportunity of speaking with two world-renowned experts in EPP and hearing news about upcoming clinical trials.



Dr. Micheline M. Mathews-Roth and Dr. Joseph Bloomer have both served on the APF Scientific Advisory Board for decades. They have produced the EPP educational materials we distribute and advised doctors throughout the United States and internationally on the diagnosis and care of EPP. Dr. Roth is a dermatologist and Erythropoietic Protoporphyrria (EPP) researcher at

Harvard University and Brigham and Women's Hospital in Boston. Dr. Bloomer is a hepatologist who researches EPP and treats EPP liver damage. He directs the Liver Center at the University of Alabama-Birmingham.

Dr. Roth opened the call by outlining the enzyme defect in EPP, its inheritance and symptoms—extreme photosensitivity that can cause painful burning, itching, swelling and redness of the skin on minimal exposure to visible light, leading to liver damage in a

minority of cases. (Please see our website for detailed information on EPP.) Dr. Bloomer then gave us the latest news about clinical trials for a new EPP treatment.

As APF members know, the FDA has approved a new drug called Afamelanotide for clinical trials in the U.S. **afamelanotide** (formerly CUV1647), from Clinuvel Pharmaceuticals, has already had encouraging results in Europe and Australia.

Dr. Bloomer explained that Afamelanotide works in part by increasing the skin's production of melanin and significantly increases tolerance to light. He informed us that Dr. Elisabeth Minder, who has conducted the afamelanotide clinical trials in Switzerland, reports that so far, patients receiving the medication saw their tolerance to artificial light increase 11-fold!



It is very exciting to know that there may soon be a new and effective treatment for EPP, and we all want more effective therapeutic options!

(Continued on page 7)

Acute Porphyrias: Who is Treated and How?

This Spring, the APF mailed a survey to its members with acute porphyrias requesting anonymous feedback on several demographic and management variables. With almost 400 respondents, this is the largest reported survey of U.S. patients with acute porphyria to date.

The purpose of the survey was to help understand and summarize current practices for managing acute porphyria attacks in the United States. The results show that acute porphyria patients are being treated according to the recommendations of experts in publications like the *Annals of Internal Medicine*, and that both men and women with at least three types of acute porphyria (Acute Intermittent Porphyria, Variegate Porphyria and Hereditary Coproporphyria) are receiving Panhematin.



The survey found that:

- Most patients who were treated received both glucose and Panhematin therapy as outpatients (in a clinic or infusion center rather than during a hospital stay). Historically, these therapies were thought to be administered in inpatient settings.
- Both men and women are receiving Panhematin, despite the labeling that indicates use in women with AIP attacks related to the menstrual cycle.
- Previously published literature and opinion have suggested that hemin is more stable and causes fewer side effects when administered with albumin. This survey provides evidence that this practice is the standard of care.

ER Resources for Acute Porphyrias

Physicians treating attacks of acute porphyria (AIP, VP, HCP & ADP) now have several resources to help them manage patients in an emergency. If you or someone you love has acute porphyria, please make sure the treating physician is aware of these resources:

ER Guidelines for Acute Porphyrias

The *Emergency Room Guidelines for Acute Porphyrias* cover basic information an ER physician needs to recognize, diagnose and provide life-saving treatment for an acute porphyria attack. Guidelines include:

- Common precipitating factors for the acute attack
- Typical presentation and other diagnostic clues
- Making the initial diagnosis
- Common complications of an acute attack
- Hemin therapy for acute attacks

These guidelines are for physician use. The APF sells a separate, personalized Emergency Room Kit that contains all the information acute porphyria patients need to have with them in the Emergency Room (medical journal articles, information about diagnostic labs and Panhematin, and a place to keep your own diagnostic test results).

Drug Safety Database for Acute Porphyrias www.apfdrugdatabase.com/

The database contains expert assessments of the potential of drugs to provoke attacks of acute porphyria and is intended for use by health care professionals. Compiled by Bo Zhou and Peter V. Tishler, M. D., Channing Laboratory and Genetics Division, Brigham & Women's Hospital, Boston, MA. **Revised Spring, 2009.**

Treatment & Testing: Beware the Snake Oil Salesman!

In the past we have placed warnings in this newsletter about websites that promise healing remedies for porphyria. Many of these sites claim to be backed by clinical trials and to offer products that cure porphyria. If only that were true!

Please remember that even certain herbs and supplements can be unsafe and can cause an acute attack of porphyria. Also, if a product is "natural" (comes from nature), it can have an unwanted effect—like eating a poisonous mushroom or being stung by a bee.

Make sure you speak with your doctor about any additive, supplement or pharmaceutical before you take it and that you rely on trustworthy sources—like our website or those of the National Institutes of Health—for your medical information.

Be equally aware of companies that purport to perform or sell porphyria tests directly to consumers or patients. As with any medical test, science and experience count. If it looks too good, too cheap, too easy to be legitimate, it probably is!

If you would like information about treatment options for porphyria or about laboratory testing, or if you would like us to send information to your doctor, please call the APF office toll-free at **1-866-APF-3635**.



Porphyrins & Porphyrias in Stockholm



Several experts connected with APF presented research findings at the Stockholm meeting. Dr. Charles Marques Lourenço, MD, (left) a *Protect the Future* program participant in Brazil, gave a paper on a potential lab test for acute porphyria-induced paralysis.

Dr. Chul Lee, a PhD *Protect the Future* participant at the University of Texas Medical Branch, spoke about the importance of quantitative

measurement of plasma porphyrins for diagnosis and monitoring of the cutaneous porphyrias. He noted that while the fluorescence emission scan is often used to screen for Variegate Porphyria, plasma total porphyrins are tested much less frequently, even though they are almost always increased in cutaneous porphyrias. Total plasma porphyrin measurement is the first-line test of choice when cutaneous porphyria is suspected. (Urinary ALA and PBG is the first-line test for the acute porphyrias.)

Dr. Karl Anderson, who directs the Porphyria Center and Laboratory at the University of Texas Medical Branch in Galveston presented research done with Dr. Lee and Jeffrey Wickliffe, PhD



(left) of Tulane University. They examined differences in a few genes between patients diagnosed with porphyria cutanea tarda (PCT) and volunteers without PCT, looking at the relationship between these genes and known risk factors for the disease like drinking alcohol, smoking tobacco, and liver disease. Dr. Anderson also reported on the long-term

response of ALA-Deficiency Porphyria (the rarest form of acute porphyria) to heme therapy.

Discussing the disease with other doctors and learning through

them about the experiences of other patients is a central part of understanding effective diagnosis and treatment of the different forms of porphyria most effectively. That's why the APF sponsored several participants in our *Protect the Future* program to attend the Stockholm meeting.

Continuing research like that presented in Stockholm is also a vital part of making progress toward better diagnostic practices, more effective therapies, and eventually a cure. Our Scientific Advisory Board and its peers have made tremendous advances in the way porphyria patients are treated, greatly improving our care and prognoses. Protecting our Future means fostering a new generation of experts to carry on this work. Other U.S. experts with presentations at the meeting were: *The biosynthesis of heme in the liver and in erythroid tissue.* (James Kushner, MD, University of Utah) • *Spatial logistics for enzymes of heme synthesis.* (Harry Dailey, PhD, University of Georgia) • *Role of heme oxygenase in regulation of heme degradation and heme biosynthesis in normal and disease states.* (Nader Abraham, PhD, New York Medical College) • *Altering the kinetic mechanism and increasing catalytic proficiency of 5-aminolevulinic synthase by targeting non-catalytic residues.* (Gloria Ferreira, PhD, University of South Florida) • *Mutations in a novel mitochondrial transporter gene cause autosomal recessive congenital sideroblastic anemia.* (Sylvia Bottomley, MD, University of Oklahoma) • *Protoporphyrin hepatopathy: Combination therapy including hemin and transfusions and course of an unexpected pregnancy.* (Gagan Sood, MD,* Baylor College of Medicine) • *A single active site of uroporphyrinogen decarboxylase is sufficient for full catalytic activity.* (John Phillips, PhD, University of Utah)

Doctors Robert Desnick, PhD, MD (Mount Sinai Medical Center, New York); Bradley Freilich, MD* (Kansas City, MO); Lawrence Liu, MD* (Mount Sinai Medical Center, New York); Neville Pimstone, MD (Veterans Administration Hospital-West Los Angeles; UCLA) and Manish Thapar, MD* (University of Missouri, Columbia) attended as well.

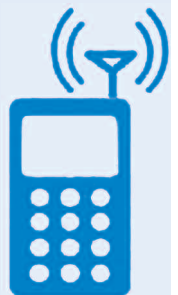
*Participant in the APF **Protect the Future** program. See our website for more information about how this program is training a new generation of porphyria experts.

Special Telephone Conference for Physicians

The APF plans to host a series of three large conference calls for physicians. The calls will be organized according to diagnosis: Porphyria Cutanea Tarda, Acute Porphyrias (AIP, VP, HCP) and Erythropoietic Protoporphyrin. There will also be a special call for doctors treating EPP to discuss the upcoming clinical trials for afamelanotide (see article, p. 1).

Please notify your doctor that we will host a telephone conference in which they can consult with a porphyria specialist on major issues in your care. The experts will offer a presentation on a different type of porphyria at the beginning of each call, and then discuss cases brought by the participating physicians.

This is a great opportunity to help your doctor offer you the most advanced care for your type of porphyria. Please encourage your doctor to attend. If you would like us to contact your doctor with information and schedule regarding these calls, please call our office with the doctor's name and mailing address.



Judy Phelps: A New Porphyrria Educator



The **Thermo Scientific Rapid PBG Kit** Judy mentions here can be run in most any hospital laboratory to quickly test a random urine sample for porphobilinogen (PBG). According to porphyria experts: "measurement of porphobilinogen (PBG) in urine can be relied upon for screening for the acute porphyrias when there are neurological symptoms such as abdominal pain."

The American Porphyrria Foundation and Thermo Scientific (maker of the Rapid PBG Kit to test for acute porphyria) gave me an incredible opportunity by asking me to volunteer at the Digestive Disease Week convention in Chicago at the end of May. Luckily I was well at the time and it was a wonderful experience!

Working with Terri Kitkoff from Thermo, we informed researchers, MDs and other health professionals about the acute porphyrias (AIP, HCP, VP and ADP), their symptoms and diagnosis. Our hope was to bring some awareness to this disease and to the correct method for diagnosing it.

Many of the doctors' first reaction was that porphyria "is too rare," or "I never see porphyria." I asked them if they ever had patients with unexplained abdominal pain, tachycardia, electrolyte imbalance, constipation, muscle weakness and mental changes? They all answered YES, and I told them that these were my symptoms too every time I went to the emergency room, and that YES I have acute porphyria. Most of the time the doctors would then sit down with me, ask questions, ask for literature and inquire about the Rapid PBG Test Kit. Some even promised that if

they had a patient with these symptoms they would remember us and order the Rapid PBG Test Kit.

In addition to the PBG Kit information, we passed out literature from The American Porphyrria Foundation (including an article from the *Annals of Internal Medicine* by top acute porphyria specialists), and Lundbeck, Inc. about Panhematin treatment for acute porphyria. We also gave the doctors information on laboratories that are experienced with porphyria testing, and on experts who can consult and advise on treating porphyria.

It was exciting to meet with many of the Lundbeck (formerly Ovation) team, I feel they saved my life with the two years of Panhematin treatments I went through. They were extremely helpful throughout that time, so it was great to finally meet some of them.

I also spent some time with the National Digestive Diseases Information Clearinghouse team (part of the National Institutes of Health branch that deals with porphyria). Their website was also very helpful in the beginning when I was first diagnosed with porphyria and looking for answers.

The first time I heard the word porphyria was in December 2005 from a doctor who was fresh back from a medical convention. He remembered the porphyria presentation when he saw me and that was the first step to diagnosis for me. So I hope someone we talked with will also remember in time to help another patient.

I urge you if you are asked and are well enough say yes and volunteer. It is such an amazing experience, you won't forget it!

— **Judy Phelps**

Thank you Judy, for all your help!

Porphyria and Health Care Reform and YOU

When an issue arises as important as the upcoming Health Care Reform, it is important for the APF to learn about how it affects people with porphyria. As you have seen in the news, this is an issue that is very controversial.

Our APF members have expressed their concern about the proposed plan. Pouring through this legislation is labor intensive but very important to your health now and in the future. After spending over eight hours studying the 1000+ pages of the HR 3200-Health Reform plan, I came away more confused about some issues, with a better understanding of others and very upset over some of the plan that was important to me personally.

Over the past almost 30 years, I have had experience helping our members with the government/state health care plans and agencies like Medicaid. Often, they did not have porphyria identified as a disease, or they did not have the type of porphyria and its relative treatment listed properly. This caused multiple repeated treatment and reimbursement issues just on a state level. Some of you have asked if it will work better on a national level.

Members questions about the HR 3200 plan primarily concerned: Medicare cuts, taxes on private plans, timely access to treatment, rationed care, the ability to keep your own doctor, access to specialized treatments, the role of the Health Choices Commissioner and his/her proposed department, the existing shortage of primary care doctors, the cost of the program, and

many other reimbursement issues.

The most prevalent question posed from our members was: Does the plan guarantee that those on the plan can keep their own doctor? According to Dr. Sanjay Gupta, keeping one's own doctor is not guaranteed in the plan. This is important to people who have invested a great deal of time educating their doctor on porphyria.

The APF motto has been, "Those who know the most, do the best." Therefore, each of you should learn about how the health care reform will affect YOU .

We have provided information below to help you assess the plan for yourself:

To read the text of the HR 3200 see Health Choices Plan, see: www.opencongress.org/bill/111h3200/text

To express your opinion or ask questions of your Representatives and Senators, please see the websites below.

However, although email is an easier means to communicate, writing a letter or telephoning your Congressmen's office has been shown to be more effective than just sending an email.

To find the address of your representatives, see: www.house.gov

To find the address of your senators , see: www.senate.gov

If you have questions for the APF, please contact Desiree at lyonapf@aol.com

Congratulations James True!



APF member James True completed the endurance- and will-challenging Ironman Triathlon on Sunday, June 21, raising \$3700 for the APF in the process. That effort makes James a hero to all APF members — he signed up with the

Janus Charity Challenge, which matched donations from the True family and friends, and from APF members, dollar for dollar.

The race was an all-day effort of swimming, bicycling and running. James took on this challenge to support his wife Debra, who receives Panhematin regularly for HCP. James wrote:

I've watched Debra battle this disease every day and not give up. As her husband, there isn't anything that I can do to relieve her pain. But I can help in another way.

On June 21st my battle will be a 2.4mi swim, 112mi bike and a 26.2mi run. My battle will end at the finish line but [the battle against porphyria] will continue. With your help we can increase awareness and research for a cure. Please help however you can.

Thank You James, and Congratulations! Thank You to all who donated for this special event!

Is That a Donation in Your Closet?

Do you have gently-used clothing hanging in your closet? Now you can turn those clothes you don't wear into a donation to the APF.

Member Monica Firchow is co-proprietor with Tamara Stavrianoudakis in Upscale Resale Consignment Boutique in Templeton, CA. The shop resells upscale women's clothing and accessories (Saks, Nordstrom's, high-end designers, Ann Taylor, etc.), and returns after-cost proceeds to the original owners. Tamara and Monica have generously offered to sell items from APF members as a fundraiser for us, and to donate their own costs, passing all proceeds from these sales on to the APF.



Monica first told me about the shop when we staffed the APF booth together at The Liver Meeting last year when she and Tamara were in the middle of their search for retail space. By the time we got together again for the American Society of Hematology meeting one month later, they had rented and remodeled a shop and opened for business. Monica and Tamara know how to get things done!

For more information on donating your used items to us through Upscale Resale, call me at the APF office: 1-866-APF-3635.

— **Mira Geffner**

Lyon's Share

The APF is not a large organization built by an even larger corporation. Instead, we started as a small group around my kitchen table and grew together—you and me. We built the APF together and share in each success. For example, with your suggestions and your help, and even your appearances on local and national television and radio programs, the APF has received more media than any other rare disease.



We are fortunate that our Scientific Advisory Board is involved with us on a daily basis—developing and updating our educational material and consulting with physicians who seek their expertise. When we came to you for funds to help these experts train a new generation of porphyria specialists, you responded and made our *Protect the Future* program a reality.

We try to respond to YOUR needs. The recent *Emergency Room Guidelines for the Acute Porphyrias* was published to help ER doctors diagnose and treat patients quickly.

Because the APF is all of us, I don't hesitate to tell you that we have been hit by the economic downturn. We ask that you help in your own way. You may choose to send a donation, or host a bake sale or a car wash. Your suggestions are helpful and include donating auction items, or airline miles or hotel points that we can use to defray the costs of exhibiting at a medical meeting.

If you live in the Houston area and can donate one day each week to help answer the office phones and prepare mailings, we would be so grateful.

Together we will forge through these difficult times. Thank you for the many years of friendship we have had together.

— **Desiree Lyon Howe**

Cathleen Mouledoux: An EPP Family in Texas and Australia

Cathleen Mouledoux does not have porphyria, but her husband Rene and their daughter Celeste do. Cathy reports that while Rene was always fair, he played outside all the time as a child and never had anything more than a sunburn. He was only tested for Erythropoietic Protoporphyrin after he and Cathleen found out that Celeste has EPP.



Celeste had always shown low tolerance for the sun from the time she was a baby. The first time Cathleen noticed the problem Celeste was still crawling—she was playing outside in dappled sunlight, mostly shaded by a large tree, and she suddenly started crying inconsolably. When Cathleen took her indoors, she saw that Celeste was browned on her nose and her cheeks. She browned like that a few times

as a child, and her skin would peel afterwards. But rather than peeling like a sunburn, the skin would come off in big chunks.

As a toddler Celeste had a bad burning sensation in the skin on her hands, but no visible symptoms. At age four, she broke out in tiny little bumps after being out in the sun. The bumps look like bug bites and the family called them “spider eyeballs.” Celeste continued to suffer terrible pain with sun exposure.

When Celeste was 13 years old, her mother learned that two cousins had a disease called Erythropoietic Protoporphyrin. Their symptoms were similar to Celeste’s—all three kids would experience dramatic swelling in their hands and faces whenever they played in the sun. Cathleen took Celeste for testing and the

diagnosis was made.

Not being able to tolerate outdoor activities as a child was hard on Celeste. Cathleen remembers her daughter going to the beach with a group of friends one day as a teenager, getting major sun exposure, and coming home bright red with her skin hugely swollen and painful. Celeste’s arms swelled dramatically all the way up to the bottom of her t-shirt sleeves and the swelling and pain took six weeks to heal completely.

The one reprieve came when Rene’s job moved the family to Australia for several of Celeste’s high school years. Sun protection has been popularized in Australia because skin cancer is a major problem there. Broad-brimmed hats were part of the school uniforms, and children’s’ bathing suits often offered as much coverage as shortie wetsuits.



Now Celeste is a young woman in her early 20s and doing well. She knows what she needs to do to protect her skin from the sun, and while—like many patients—she chafes against the restrictions of covering up with protective clothing and titanium-dioxide sun block, she does it to stay healthy.

In Memory

We are saddened to hear of the passing of our dear friends. Some of their loved ones have chosen to honor a life by making a gift to the APF. We sincerely appreciate their thoughtfulness and desire to help others with the disease. Please join us in thanking: Douglas E. Jenne for John Giacobbe; Charlotte and Dennis Homan, Joan and Allan Morris, The Adrian Chandler Family, Norma Sue Glenn, Katherine and John Dugger, Betty S. Brooks, Carol and Ralph Wesley, Jr., Dr. Christine Caufield, John Kieffer, Tracy J. Welker for Norma Kelton Lambert; Grace and John Mikulich for Eugene Nielson; Donald L. Johnson for Peggy Lewis Johnson; Margaret Lawson for Rita Bell Mead; Diane L. Levere for Dr. Richard D. Levere; Kathleen Toelkes for Donna Pagano; Genevieve Reynolds for Lawrence Reynolds.

In Honor

Others have chosen to honor their friends through a gift to the APF: Kathleen E. Venter for Patti Wright; Barbara A. Kaiser, Louis E. Kaiser for Richard Dugger; Suzanne Spinrad and Edward Geffner for Alan Ravitz; Sylvia and Alan Ravitz for Stanley Fabricant; Linda and William Steward for Crystal L. Stewart; Sharon I. Koch for Matt and Wendy Koch.

The American Porphyria Foundation is working to improve the health of those who suffer with these rare diseases by educating physicians and patients, and by supporting advanced training for a new generation of porphyria experts.

*If you wish to send a gift in honor or in memory of someone, please tell us your name and address so that we may acknowledge your gift. Please also include the name and address of the individual in whose name you are giving for **In Honor** gifts, or the name and address of the deceased's loved one for **In Memory** gifts, so that we may inform them of your kindness and sympathy.*

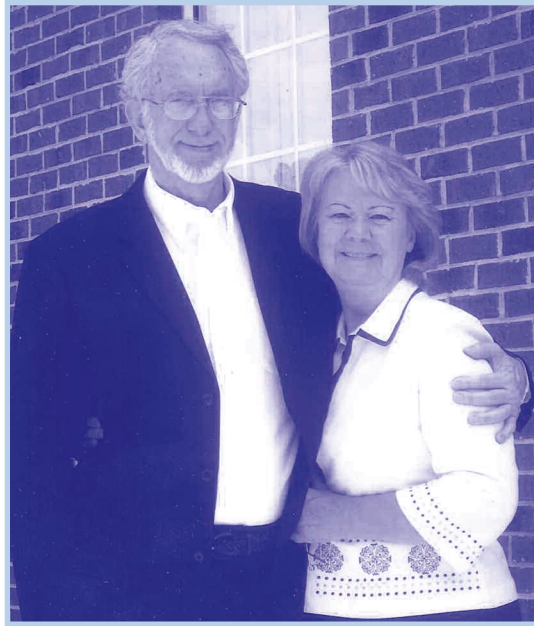
Tom Collier: A Long Road to Diagnosis

After suffering a near-lifetime of symptoms, Tom Collier was finally diagnosed with EPP about five years ago, when he was 64 years old.

Tom remembers running around screaming after being in the sun as a little boy, and having horrible pain all over his hands, arms and legs. Yet like many children with EPP he had no visible symptoms. He didn't swell up or get red, but his parents knew he was suffering every time he went outside.

Tom's brother (who also has EPP) stumbled on the term Erythropoietic Protoporphyrinemia several years ago and thought the description matched both their symptoms. The search for a doctor who could help led Tom to Dr. Joseph Bloomer, who ordered lab tests and sent them to the Porphyria Center at the University of Texas Medical Branch in Galveston, where they quickly made the diagnosis of EPP. Shortly afterwards Tom called Dr. Micheline Mathews-Roth, and spoke with her at length.

By that time, Tom was already used to covering up to go outside and avoiding the outdoors during daylight hours. He says when he first sets foot outdoors the sun feels warm on his skin, just like it does for anybody else. But before long he becomes a bit uncomfortable in the sun, and that's his signal that it's time to get



inside right away. After the discomfort comes the prickling, stinging, burning pain of EPP.

Stepping into the shade when he has to be outside is helpful to Tom, but he does get EPP symptoms from indirect light as well. Indoors, he feels the sting of fluorescent bulbs, and incandescent bulbs bother him somewhat too.

Tom notes that today, most doctors he encounters are familiar at least with the basics of porphyria. This makes a big impression on a man who lived 60 years with a severely photosensitizing disease and no diagnosis. Tom and his brother both spent much of their lives figuring out on their own what set off the symptoms of EPP and how to stop them.

It's easy to become impatient with the pace of rare disease medicine, the difficulty of diagnosis and the lack of a cure. But we've come a long way in the past 70 years: from a little boy whose parents could find no answers, to a name for the disease, a clear genetic marker and a blood test to diagnose it. Porphyria patients today owe a tremendous debt to the doctors who worked to discover the biological secrets of the disease, and to patients like Tom, whose experience helped educate doctors, to the benefit of us all.

EPP Conference Call (continued from page 1)

For EPP patients it would be wonderful to be able to withstand and even enjoy more time in the outdoors, and to gain potential benefits for liver health. Being able to better avoid flare-ups from EPP is an important treatment goal, as Dr. Bloomer and Dr. Roth both noted that the main treatments available for the pain of EPP symptoms are aspirin, Tylenol (acetaminophen) and cold compresses.

Dr. Bloomer encouraged everyone interested in the trials to stay in touch with the APF—we will let you know as soon as we have concrete information about afamelanotide trials.

Almost all of the call participants wanted to know if they will be able to participate in **afamelanotide** trials and when the trials will start. Here we summarize some of the remaining issues addressed during the call—a full account is on our website.

• **Liver disease.** Dr. Bloomer stressed that very few people with EPP will develop liver disease, and that the best way to prevent liver disease is through vigilance and prevention: protect your skin carefully and have your doctor check your protoporphyrin levels at least once a year.

• **Surgical lights.** Dr. Bloomer said it is absolutely necessary to cover surgical lights with UV protective films in EPP liver transplant surgery to prevent burns to the skin and internal organs. It is good caution to use the same films in other surgeries on EPP patients as well.

• **Drug safety in EPP.** Both doctors stressed that EPP patients should avoid drugs, like estrogens, that are known to block the flow of bile. But Dr. Bloomer cautioned against confusing the medication issues in EPP with those in the acute porphyrias—the drug precautions for acute porphyrias do not apply in EPP.

• **Donating blood, organs and bone marrow.** EPP patients should absolutely not donate bone marrow, to avoid giving EPP to the marrow recipient. Donating whole blood and organs other than the liver should be safe.

• **Current recommendations** for the annual blood tests for EPP patients are on our website at www.porphyrifoundation.com/about-porphyrin/types-of-porphyrin/EPP ~ Dr. Roth's recommendations for an EPP medic alert bracelet: www.brighamandwomens.org/eppref/Patient/medicalert.aspx ~ For UVF protection, Dr. Roth recommended Llumar auto glass film: www.llumar.com/en/Automotive.aspx ~ COTZ Total Block (with Titanium Dioxide and Zinc Oxide), available from sunprecautions.com ~ coolibar.com and others, as sunblock; and mentioned the Solumbra line of clothing from www.sunprecautions.com



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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: Full-length versions of the member stories in our newsletter.

Resources for Doctors:

Emergency Room Guidelines for Acute Porphyrias (AIP, VP, HCP, and ADP) for ER physicians on our website.

Safe/Unsafe Drug Database for Acute Porphyria at www.apfdrugdatabase.com/

Upcoming Conference Calls — discuss a case with a porphyria specialist in conference calls focusing on PCT, the acute porphyrias and EPP! (See page 3).

Is Your Membership Up to Date? Stay current on upcoming clinical trials, best practices for diagnosis and treatment, and upcoming events. Please take a moment to renew at our website, or call us at the office: 713-266-9617 or 866-APF-3635. Thank you.

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