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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

Is Your Membership and Contact Info Up to Date? The APF is able to maintain our physician and patient education programs and many other services because of your support. Since we do not receive government funding, we need your support and donations. We also need your new contact information if you have a new address or email. Be sure to send us your email address so you can receive the ENEWS.

Protect the Future program to train future experts is important. Please consider making a donation to this program. Yours and your children's future health depends on each of us supporting the training of doctors who will know how to treat us and perform research when our present experts retire. We have the opportunity to fund this training now so that the present expertise is not lost. Please send your donations to the APF and mark them PTF. They will be placed in the PTF fund to be used for the training of young doctors as future porphyria experts.



Merry Christmas, Happy Hanukkah, Happy Holidays Happy, Healthy New Year



May you be blessed with happiness, good health, love and the delight of being with family and friends this wonderful Christmas and Holiday Season. The opportunity to serve you and your family during this past year has been a gratifying experience for us. Our staff and support volunteers look forward to meeting and assisting you throughout the upcoming

Happy, Healthy New Year. God Bless YOU!

Yvette, Elizabeth, Susan, Carol, Warren, Desiree and Facebook Team, Rob, Amy C, Amy B, Victor, Ben, Pierre



Akshata Moghe, MBBS, PhD is our newest **Protect the Future** (PTF) doctor. As a reminder, the PTF program was designed to prepare for the void that will be created upon the retirement of our present group of experts. Twenty young experts have been trained via the APF-PTF program. Dr. Moghe became acquainted with the porphyrias and the PTF program when she attended a conference and met Dr. Karl Anderson, director of the University of Texas Medical Branch Porphyria Center and Laboratory, as well as Co-Chairman of the Porphyria Research Consortium. Her interest in the porphyrias led her to UTMB where she has been working with Dr. Anderson since February as the Clinical Research Coordinator and Research Associate. According to Dr. Moghe, "It has been a wonderful experience learning from Dr. Anderson and the porphyria patients at UTMB. I hope to continue to grow as a porphyria physician and researcher under his mentorship." The APF is grateful to have such an esteemed young doctor help us *Protect Your Future* health.

Dr. Moghe earned her 2007 Bachelor of Medicine and Bachelor of Surgery at the Seth G.S. Medical College and King Edward VII Memorial Hospital in Mumbai, India where she also attended the Maharashtra University of Health Sciences. She graduated with Distinction honors in Anatomy, Biochemistry, Pharmacology, Pathology, Microbiology and Forensic Medicine. In 2010, she went on to earn a Master of Science in Pharmacology and Toxicology and a Doctor of Philosophy in Pharmacology and Toxicology at the University of Louisville, KY.

Dr. Moghe's Clinical and Research positions include her present position at the UTMB Porphyria Center, Dept. of Preventive Medicine and Community Health in Galveston, Texas. Her previous position was as graduate Research Assistant at the University of Louisville, School of Medicine where her research focus entailed the role of chromatin remodeling in curcumin-mediated regulation of gene expression in hepatocellular carcinoma. Prior to that she worked at the National Institute for Research in Reproductive Health (NIRRH) in Mumbai focusing on viral variants in blood and semen of HIV infected patients and their association with disease pathogenesis. Aside from her heavy work schedule, Dr. Moghe is involved in a number of volunteer community services, like counseling high school students on clinical and research career options in the medical field, conducting medical camps and AIDS awareness projects, as well as serving as a volunteer for leprosy, vaccinations, flood relief and bomb blast relief to name a few.

Among her many Fellowships, Scholarships, Honors and Awards are:

2002, 2003 and 2004 Ratan Tata Scholarship for Academic Excellence in Medicine/Surgery

2012 Department Scholar Award, School of Interdisciplinary and Graduate Studies (SIGS), University of Louisville

2012 Sponsored Research Tuition Award, SIGS, University of Louisville

2012 The Guy Stevenson Award for Excellence in Graduate Studies, the university's most outstanding doctoral degree recipient who excels in scholarship, leadership, and other areas within their discipline, University of Louisville

2012 Commencement Speaker, Doctoral Hooding and Graduation Ceremony, Freedom Hall, University of Louisville

2013 K.C. Huang Outstanding Graduate Student Award, Pharmacology and Toxicology, University of Louisville

Below are a few of her upcoming publications:

1. **Akshata Moghe**, Bryan Lamoreau, Mohammad Mohammad, Shirish Barve, Craig McClain and Swati Joshi-Barve, *Mechanisms of Acrolein Toxicity: Relevance to Human Disease* (under review, *Free Radical Biology & Medicine*)

2. **Akshata Moghe**, David Barker, Smita Ghare, Leila Gobejishvili, Swati Joshi-Barve, Craig McClain and Shirish Barve, 'Promoter histone acetylation plays a major role in the reactivation of tumor suppressor *TFPI-2* gene expression in hepatocellular carcinoma' (in preparation)

THE "PTF" PROGRAM TO TRAIN FUTURE EXPERTS IS SUPPORTED BY YOUR DONATIONS.

Thank YOU for supporting this program in the past. Please help us to continue the "PTF" program.

If you would like to support the "PTF" program, please mark your donations "PTF."

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Panhematin@News Panhematin®, the only commercially available heme therapy in the United States, was purchased by the Recordati Rare Diseases (RRD). Therefore, the method to order Panhematin® has changed. Please advise your doctors and hospitals of the new means to contact RRD to order the treatment or gain assistance. Healthcare providers can place their order through their primary wholesaler or call [866.654.0539](tel:866.654.0539) or fax [614.553.0539](tel:614.553.0539). Shipments will be delivered in a shipping box from ASD Healthcare via UPS Next Day Delivery. For assistance, call [866.209.7604](tel:866.209.7604), M-F 8AM-5PM CT. RRD medical information. Contact: [888.575.8344](tel:888.575.8344) or medinfo@recordatirarediseases.com.



Continuing Medical Education (CME) Course Physicians are required to have Annual Continuing Medical Education (CME) courses. Fortunately, YOUR doctors have the opportunity to take this outstanding CME course about Acute Porphyrias and receive FREE CME credit. Please tell your physician about this course, which was offered last year and has been brought back by demand and is offered at the following link. CME courses require registration but most physicians are already registered. Registration is free and simple.

Acute Porphyrias: Recognition Through Follow-Up CME
<http://www.medscape.org/viewarticle/712889>

Porphyria experts, Herbert L. Bonkovsky, MD; Manisha Balwani, MD, MS; Karl E. Anderson, MD; Brendan Martin McGuire, MD, MS (*in photo*) are the Faculty. CME for credit is valid through 07/08/2014.

This activity is intended for hematologists, gastroenterologists, primary care physicians, emergency medicine physicians, obstetricians/gynecologists and other healthcare professionals who may encounter patients with the acute porphyrias. The goal of this activity is to provide an informative discussion on some of the major issues associated with acute porphyrias, including recognition, evaluation, treatment, complications, and prevention.

Upon completion of this activity, participants will be able to: Recognize signs and symptoms of and conduct appropriate testing to promptly and accurately diagnose the acute porphyrias, evaluate current recommendations and emerging approaches for the management of the acute porphyrias and discuss complications associated with the acute porphyrias and their treatment.

Emma Gonzalez-Rivera *"I live in Sorrento, Florida now, but I lived near the Mohave Desert for the last 14 years. I don't know if I was born with PCT, but I always had health problems. Menopause was too early, and the gynecologist put me on the Estrogen therapy. Eventually, I got endometrial cancer and had a complete hysterectomy. For one year everything seemed to be fine. Then my urine turned very dark, and I began to get frequent bladder infections. I continued to visit the ER very often and my skin began to get dark, especially on my forehead and cheeks and hair grew on my face. Doctors did not know what was making me sick even when my liver enzymes were very high. I was so ill my sister cried when she saw me. Desperate, I visited a dermatologist. When he reviewed my case, he wrote, Porphyria Cutanea Tarda, and asked me to research it. He took a skin biopsy and blood tests. He was correct. I had PCT.*



Now I have a good hematologist who keeps in touch with Dr. Casey, the dermatologist - my hero. The first year I began the phlebotomy treatment. I had it done every month and sometimes every two weeks. Now I have it every six weeks depending on the ferritin level. I feel tired and not well, but once I have the phlebotomy, I am full of energy. My skin is a bit lighter and the urine is normal. The liver enzymes are almost normal and the facial hair is controlled. I still have to stay away from the sun and my skin is fragile. If you have PCT, I know how you feel, but you just have to learn how to live with it with patience and faith. You will get well. God Bless You!"

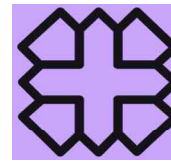


Notice from Dr. Peter Tishler *"I hope you have been using the APF Drug Database (<http://APFdrugdatabase.com>), which we established some years ago. I am updating the drug database once again, to add new medications and reinforce or change the safety of existent medications. Thus, I write once again to ask all APF members with an acute porphyria (acute intermittent porphyria AIP, variegate porphyria VP, hereditary coproporphyrin HCP, ALA dehydratase deficiency porphyria ALAD) to provide information regarding your medications."*

Dr. Tishler, who is a porphyria expert and genetics professor at Harvard Medical School, has voluntarily maintained the drug list for the APF for many years. The APF and our 5000 members express our sincerest thanks to Dr. Tishler, not only for his enormous work with the drug database, but also for helping so many porphyria patients who are devoted to him as their physician. His recent publication,

The rise of pathophysiologic research in the United States: the role of two Harvard hospitals. (*Perspective in Biology and Medicine* 2013 Spring;56(2):244-50. doi: 10.1353/pbm.2013.0010) is very interesting and concerns a major approach to understanding and treating disease.

Editor's Note: If you have not received the **Evaluation of Medications for Acute Porphyrias** form from the APF and Dr. Tishler, we can send you another one soon. You can request a form via email porphyrus@aol.com or call the APF 866.APF.3635. Sharing your experience about a specific medication can be very helpful, so your participation is greatly needed in this project. Please return the form to the APF as soon as possible. It will then be forwarded to Dr. Tishler.



The APF and YOU! For over thirty years, the APF has been the only foundation and main source for porphyria education and awareness for patients and physicians, research, support, government support and an array of patient support services overseen by a *Scientific Advisory Board* of renowned porphyria experts. The APF's award winning educational materials include the website, newsletter, E-NEWS, brochures and ER kits. Patients and Physicians worldwide seek the APF assistance, because they know that the information written is

by renowned porphyria researchers and clinicians. You have made the APF the major resource for patients, their families and physicians. Together we can make a huge impact on the medical community by expanding our physician programs with updated data on diagnosis and treatment. The APF *Protect the Future* program to train the next generation of experts needs your help to keep this very valuable program on target. Below are a few of the APF daily programs. [The APF exists to serve YOU and YOUR family but needs your donations to continue these programs and services.](#) Thank **YOU** for your support making these programs possible!

Protect our Future Health

*Promote the training of 20 future porphyria experts through the APF Protect the Future program.

Physician and Patient Education

- *Maintain and expand award winning comprehensive website, brochures, pamphlets, books and educational materials for each type of porphyria, genetics, and research,
- *Initiate and develop new educational programs and services for purposes of research, treatment, diagnosis,
- *Distribute materials on porphyria treatment,
- *Provide updated Safe and Unsafe drug lists,
- *Facilitate referral and consultation services for patients and physicians.
- *Support porphyria outreach clinics around the county
- *Produce and distribute updated Emergency Room, Primary Care Physician Guidelines, and assist the doctors,
- *Produce ER Kits for Acute/EPP Porphyrias,
- *Create, publish and distribute the quarterly APF newsletter and Internet E-News,
- *Develop additional educational programs for physicians and patients to introduce new treatments and/or diagnostic techniques,
- *Host physician and patient education conference calls with experts,
- *Produce and distribute professional DVD on porphyria; in NYC, Galveston and Houston with renowned experts,
- *Provide national and international resources for patient and physician education,
- *Maintain exhibits at targeted medical conventions and distribute educational materials,
- *Facilitate telephone and internet contact between primary care doctors and experts,
- *Promote porphyria CME courses, grand rounds, etc.

Awareness Activities

- *Promote National Porphyria Awareness Week,
- *Devise and expedite PR campaigns to enhance porphyria awareness and nationally and internationally
- *Solicit and facilitate print media, major television series, medical and news programs. Thus far, the APF has gained MORE television attention than ANY rare disease.

Research

- *Develop and distribute news updates for all porphyrias,
- *Locate patient volunteers for research and facilitate their involvement,
- *Advise physicians of ongoing and new research projects,
- *Assist with major research projects and needs,
- *Facilitate patient committee meetings,

- *Facilitate the APF Global Partners Program,
- *Facilitate clinical trials,
- *Develop and distribute materials to help patients understand research,
- *Procure and increase government funding for research,
- *Assist with clinical trials and FDA approval,
- *Assist with FDA, Office of Rare Disease, NIH, and other government agency issues,
- *Assist in determining porphyria incidence,
- *Organize fundraising activities for research,
- *Support research financially.

Support and Assistance Programs

- *Maintain our Telephone Hotline, assisting patients nationally and internationally.
- *Facilitate financial assistance programs for insurance aid,
- *Answer website, mail, email and telephone questions,
- *Facilitate and maintain the IN TOUCH, FACEBOOK, Twitter, Blog and other support group network and services,
- *Host programs for caretakers training and support,
- *Expedite patient diagnosis, support, testing and treatment problems,
- *Facilitate appointments and physician consultations with porphyria experts,
- *Help facilitate testing, diagnostic and treatment process when needed,
- *Assist with Medicare and Medicaid issues,
- *Assist patients with their needs and support.
- *Facilitate assistance programs to fund treatment.

Social Networking Programs

- *Host five FACEBOOK social networking groups for each type of porphyria and Purple Light Blog and Twitter accounts,
- *Assist Veterans with PCT/Agent Orange issues,
- *Host Patient and family gatherings and educational presentations,
- *Provide Pen Pal services for youngsters.
- *Provide FACEBOOK groups for young adults with EPP.
- *Produce new books, pamphlets and other educational materials for each type of porphyria,
- *Increase porphyria awareness around the world,
- *Procure government research funding,
- *Develop and distribute educational materials for patients and physicians,
- *Develop and distribute Emergency Room Kits and Emergency Room Guidelines,
- *Prepare and Update educational materials and website,
- *Assist researchers to locate research volunteers,
- *Assist patients to find reimbursement for health related expenses.