



**EDUCATING YOUR DOCTOR** The APF mission is to educate doctors around the country, but first, we want to make sure our members' physicians know how to diagnose and treat porphyria correctly. To those of you with acute porphyrias, the APF will send your physician a comprehensive packet upon request. All you need to do is provide us with your doctor's name and mailing address. This packet is free and contains an array of materials which have been written specifically for health professionals by porphyria specialists. The materials include comprehensive information on the diagnosis and treatment of the acute porphyrias. To date, we have over 2000 of your doctors on our APF database, which means there are thousands of you who may want to further educate your doctors with this outstanding information packet. Plus, we will enlighten them with each new discovery. However, we must enlarge our doctor packets for EPP, PCT and CEP. The ~~P~~et ~~B~~eauty Contest raised almost \$5000, which was a good start but is short of the \$10,000 mark it will take us to to develop and print new materials. Maybe you can share other ways we can do this or help with a fund raising project of your own. You can also help us in another way. For many years, the APF only gave out the names of experts. Now we also maintain a list of doctors around the country who are knowledgeable about the porphyrias. If your doctor knows how to diagnose and treat and is familiar with the unique difficulties of each of your type of porphyria, we would like to add them to our database so that other patients in your area will have access to a doctor who can potentially help them. Even if they're not experts, having some knowledge and experience treating it is valuable information for us and our members. You can also let your doctors know that we can send them information about free CME (continuing medical education) courses on the acute porphyrias. The present courses are: **"Diagnosis and Initial Treatment of Porphyrias in the Emergent Care Setting: Case and Commentary"** and **"The Management of Acute Porphyrias: Improving Diagnosis, Treatment, and Standards of Care."** If you would like your doctor to receive the CME course or the information packet by porphyria experts, please send us your doctor's information: Call (713) 266-9617 or toll free (866) APF-3635 or email [porphyrus@aol.com](mailto:porphyrus@aol.com).

**What is a CME Course** Continuing Medical Education (CME) is the term for the specific courses that physicians are required to regularly review or participate in to be apprised of the latest developments in their specialty. CME's enable them to bring the best standard of care to their practices. These courses take many forms, such as classes, both online and in person, as well as professional journal articles, tracts and seminars. The content offered in these courses most often originate with experts in a particular specialty, like the porphyria experts who participated in the above CME courses. Your doctors can earn free CME credit for porphyria as shown in the above courses.

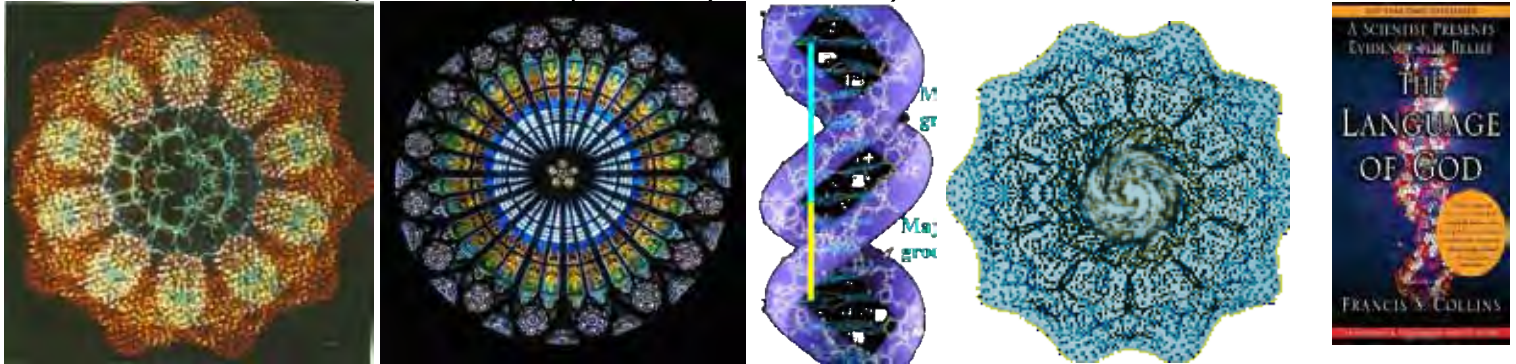


**Porphyria Research Consortium Meets** Porphyria researchers and our **Protect the Future**, "PTF", team of doctors gathered March 17-18, 2012 in Birmingham, Alabama at the University of Alabama Porphyria Center hosted by Dr. Joseph Bloomer. The Porphyria Research Consortium meets quarterly at each of the Porphyria Centers. The agenda of the meeting included these important subjects: *The National Porphyria Registry; The Longitudinal Research Update; The Mitoferrin Research in EPP patients; The Double-blind Randomized Placebo*

*Controlled Parallel Group Trial with Panhematin®; The Clinical Diagnosis of HCP; The Hydroxychloroquine vs Phlebotomy for PCT; A Study of the EPP Natural History Genotype-Phenotype Correlations and Psychosocial Impact; An Acute Porphyria Biomarker Study; Clinovel Phase III Study for EPP, as well as discussions about the **Protect the Future Program** to train future experts.* There was an intensive overview of the current training and an update on the inclusion of PTF doctors in all of the Consortium research, publications, presentations and grants. You will all be pleased with the scope and success of our PTF program. We have trained or are now training twenty young doctors as the future porphyria experts. But we need your help to expand this program and add more young doctors to be the next generation of porphyria experts.

Future Experts, *Drs. Cabellas, Narang, Thapar and Mittal* (pictured above), are needed to carry on the critical role of caring for porphyria patients going forward, because the current experts will be retiring in the next few years. These future experts learn from being mentored by the current experts, like *Drs. Joseph Bloomer, Herbert Bonkovsky, Steven Shedlofsky, Montgomery Bissell, Neville Pimstone, Karl Anderson, Robert Desnick, John Phillips* and other experts who perform porphyria research and manage our healthcare. Although we can take pride in the twenty young doctors who are now very knowledgeable about porphyria, we must add to that number. The APF cannot do this without YOUR help! It is very costly to train young doctors through the APF's "PTF" program. Please consider a contribution to this vital endeavor. You can also help by adding one, two or fifty more young doctor before the current experts are no longer in practice and, effectively, gone.

**DNA or a Rose Window** The first and last photos may look like the "Rose Windows" typical of the Medieval Gothic Cathedrals in France but instead they are cross section views of DNA. The similarity is remarkable, perhaps, because the inspiration came from the same source. DNA in the cell appears as a double stranded helix. For a fascinating explanation of the unique shape of DNA in the cell, go to <http://www.goldennumber.net/dna.htm> and be astounded. This beautiful identifier is what each one of us carries in our bodies, like a serial number. And like a serial number, it marks each and every human being as an individual, special and unique. The DNA illustrates for us that we are indeed "fearfully and wonderfully made." (Psalm 139:14)



**NIH Director Dr. Francis Collins Calls DNA "The Language of God."** The current NIH Director, Dr. Francis Collins, served as Director of the Human Genome Project, which pioneered discoveries of the human genome and genetic tracking methods. Dr. Collins' education in Chemistry at U of VA and Yale, as well as his groundbreaking work in chromosomes and as a "gene hunter," paved the way for his successful discoveries in the most important work of the past century, the Human Genome Project. Dr. Collins has authored several books, including his book on DNA, called *The Language of God*, which provides a profound argument for the integration of faith and logic. Collins raises arguments for the idea of God from biology, astrophysics, psychology and other disciplines. It has long been believed that science and faith cannot mingle. To many scientists, faith rejects the rational, while science restricts us to a life with no meaning beyond the physical. Regardless of your personal persuasion-believers, agnostics, and atheists alike, *The Language of God* will inspire you as you read Collins' personal story of struggling with doubt, as well as the many revelations of the wonder of creation that will forever shape the way people view the world.



**A YOUNG DOCTOR STUDIES PORPHYRIA** The APF is pleased to introduce Dr. Marisol Albuerne, who has been studying porphyria with expert, Dr. Karl Anderson at the University of Texas Medical Branch in Galveston, Texas. Dr. Albuerne attended the University of Houston where she graduated *magna cum laude* and then attended Medical School nearby at UTMB. During medical school, Dr. Albuerne was awarded the *Thayer Award for Excellence in Teaching*, which embodies sound scientific knowledge, compassion towards patients and dedication to learning and teaching, as well as the *Beiersdorf History of Dermatology Award*.

Born in Baltimore into a family of physicians, she settled in Clear Lake, Texas with music on her mind. Dr. Albuerne began playing classical violin at age 4 and later the fiddle at eight, thereafter, became an award winning classical pianist. But medicine, particularly dermatology, captivated her. Fortunately, during a course with Dr. Anderson, she focused on porphyria because of its cutaneous manifestations. Dr. Albuerne plans to continue her porphyria studies, research and helping the porphyria community in general. *Thank you !!*

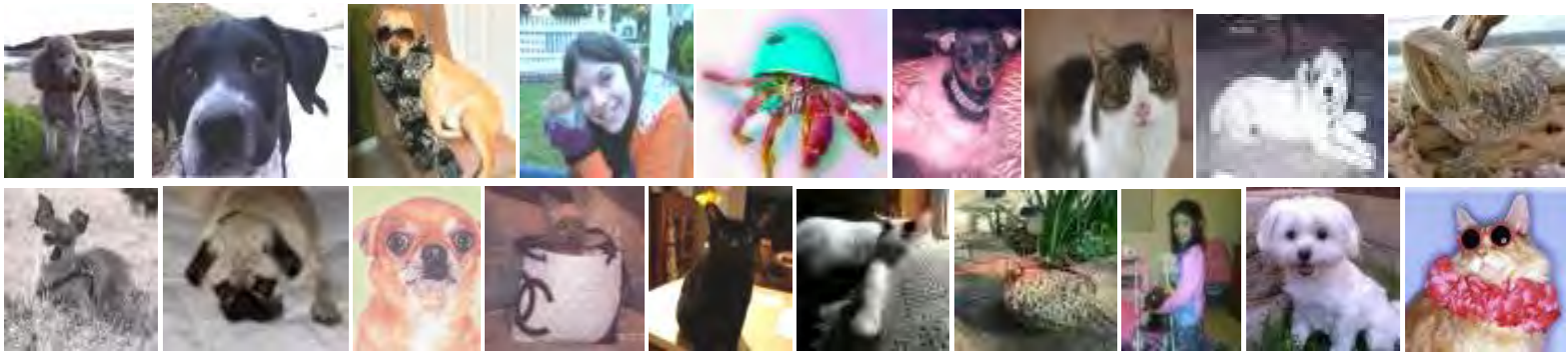
**Social Security** When warranted, the APF helps with patients with their Social Security Disability issues.



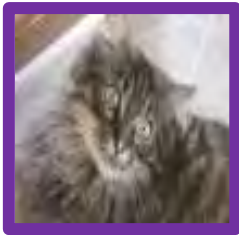
The APF has been actively involved with the Social Security office to enlighten them on the problems that many people face when they apply for disability. In turn, the APF also speaks with patients to share what we have learned that impedes or enhances the process. Over the past 30 years, the APF has had the opportunity to speak with many Social Security officials as we help patients present their cases to the Disability offices. Recently, the APF presented their cause that certain porphyrias should be fast tracked through the new Rare Disease Fast Track program. Some patients have not been able to work due to the severity of their disease. The APF has been interacting with the Social Security Department on behalf of these patients and through their discussions, has identified more circumstances that prevent the granting of disability. If you are having problems with Social Security, you can contact the APF about your case.

**Don't forget to register on the National Porphyria Registry on the APF website. Help us tell the government that we need money for research and learn the incidence of porphyria.**

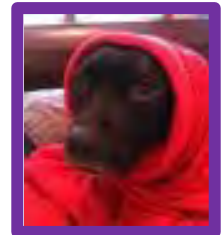
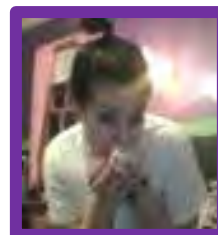
**Pet Beauty Contest Contestants** Lizards and crabs, ponies and poodles, hamsters, rabbits, turtles, dogs, cats and rocks, yes, *Rocky*, the pet rock, were all beauties in the **Pet Beauty Contest** to help fund Physician Education. Enjoy them all!!! *Row 1, L to R:* Scudo Love-Andres, Speckles Linner, Finnian Castro, Skittles Moya, The Lovely Holly Pannor, Chloe Ijames, Tippy Price, J.J. Scoggins, Hey Girl Hiley. *Row 2, L to R:*, Chico Brandt, Petey Ballerin, Trixie Crask, Tova Dzygala, Midnight Bruno, Mia Fleegle, Rocky Raines, Brownie Dawson, Amazing Grace Ohlerich, Brother. **\$5,000 was raised toward our \$10,000 goal and we had a lot of fun in the process!**



**And The Winners Are...**



**The Runner Ups Are...**



**Tiny Gillis - Money Raised & Ari Nagin - Most Votes!!! Bella Gould & Luca Yelen!!!**

It appears the Cats are hard to beat in a Pet Beauty Contest. **Tiny Gillis** (L to R) was a gorgeous outdoor cat when her owner's daughter rescued her. Tiny only weighed 2.5 lbs at 3 years old and had already had a litter of kittens. Now she weighs 10 lbs and wouldn't think of going outside even if all the doors are open. Tiny has got it made! We thank Tiny's friends for making her the *Winner* of the **Pet Beauty Contest** by raising \$900 for the Physician Education Program. **Ari Nagin**, is a very regal looking cat! He was adopted a year ago and loves cuddling, playing, lying in the sun and making his owner very happy. Ari raised \$640 to help educate doctors. We thank Ari's friends for voting and making her the *Winner*. **Bella Gould**, *Runner Up - Most Votes*. This is Jill Gould (pictured above, Runner Up) and her smiling pet rat, Bella. Jill is 15 and was diagnosed with AIP thru DNA testing at the age of 12. Bella is 3 months old and loves to be held by Jill. *Runner Up - Money Raised* is a beautiful dog named, **Luca Yelen**. Luca's mom calls him her "Babushka Baby," because he is always cold so he spends most of the day snuggled under the blankets. Luca raised \$315 for the APF Physician Education Program. Thanks Tiny, Ari, Bella and Luca! The reason we held a Pet Contest is because Pet's are very important to our health. Pets give us give us love and empathy, they look to us to care for them. Caring for the pet we love is one special motive to get well in spite of the challenge of porphyria. **Thank you all for participating!**



We are saddened to hear of the passing of family members and friends. Some of you have chosen to honor a life by making a gift to the APF to help others with porphyria. Please join us in thanking: Gary Horn for *Sandra Horn*; Marilyn and Harold Sachs for *Clara Gayle Mitchell*; Carole and Glenn Kuklewski for *Vincent Kuklewski*; Victoria and Matthew Gehm for *Judy Coley*; Rebecca and Mark Warner for *Teresa Louise Glover*; Leah and Kurtis Fletcher for *Michael J Giles*; Elizabeth H Petersen for *Anna Maria Raineri*; Willo Dean S Goode, Sylvia Acchione-Noel for *Margaret Beckham Parrish*; Fred Conover, Ruth and John Watkins, John W Looper, Patricia Wilson for *Velma D Key*; Ching-Yun Wang for *Chih-Chang Wang*.



**In Honor** We also thank those who donated to the APF in honor of a friend or family members. Arlene de la Mora, Eric S Gray, Paula Hendrix for *Ralph Gray*; Karol D Webster for *Kim Bastian*; Sonja Vertkin for *Stephanie Beck Felts*; Carolyn Y Riggs for *Russell W Riggs*; Charlotte J Beck for the *Charlotte de ne Guerre Family*; Arlene and Randy Bunker, Billye Burke, Anne L Johnson for *Candace Johnson*; Lee Ann Cook, Krissy School, Vernon Middle School for *Cason and Caul Cook*.

*The APF sincerely thanks you for honoring your family and friends in such a special way. Please know that we send a notice to the family of each person memorialized and to the person honored.*



*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](http://www.porphyrifoundation.com)

**Tell Your Doctors About the National Registry. It is very important. Your doctors may have other patients who need to know about the APF and the Registry.**

**Tell your doctor about the Safe/Unsafe Drug Database for Acute Porphyria and Emergency Room Guidelines for Acute Porphyrias. All APF medical information is written by porphyria specialists.**

**Is Your Membership Up to Date? Don't miss a newsletter! Please take a moment to renew at our website, or call us at the office: 713-266-9617 or 866-APF-3635. Thank you.**

**Contact the APF If Your Doctor Needs a Dr. Packet. We will send a comprehensive packet to your doctor free of charge. Just call the APF with your doctor's name and address and your type of porphyria.**

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