



Merry Christmas, Happy Hanukkah, Happy New Year

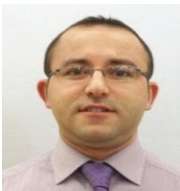
May God Bless You With His Peace, Happiness, Mercy, Joy and Good Health in the New Year. We, too, have been blessed by knowing so many of you personally and developing wonderful friendships. The experience of providing you with helpful information and support is also very gratifying. With love and thanks from the APF team, Yvette, Elizabeth, Maria, Carol, Alexis and Desirée

New "Protect the Future" Doctors We are pleased to announce that we begin the New year with two new doctors in our PTF program. In case you are not familiar with this important project, PTF is our means to assure our members that there will not be a void of experts as our present experts approach retirement. Through the PTF program, these young doctors are mentored by renowned experts to become the future experts, particularly since we have already lost most of the nation's experts. We cannot stress enough that we must continue to train the next generation of experts, because without them, there will be no expert to carry on the research, write the medical textbooks, which our own primary care physicians use to learn how to diagnose and treat the porphyrias. Together we must continue this program, but we cannot do it without funding, and the funding must come from us. The government does not support to train future porphyria experts, rather, their contention is that if we are to have doctors with porphyria expertise, the people who are affected by the disease should fund the training. So, it is in our hands to protect our future and provide porphyria expertise for ourselves and our children with porphyria. One donor has challenged us all and will donate \$100,000 when we provide a matching amount. *Please make a special contribution to help train 20 future experts through the PTF program. Mark your donations, "PTF," and your contribution will be placed toward securing a healthy future for yourself and your children.*



Vinaya C. Maddukuri, MD, is our newest **Protect the Future** trainee. He hails from the Carolinas Medical Systems in Charlotte, NC where he works with his mentor, Dr. Herbert Bonkovsky, one of the world renowned porphyria specialists. Vinaya completed his residency training in internal medicine at Saint Francis Hospital, Evanston, Illinois affiliated with University of Illinois at Chicago in June 2006. He worked for five years as internal medicine faculty and hospitalist at University of Cincinnati, Cincinnati, Ohio and completed a one year fellowship in Hepatology and Liver Transplantation at Carolinas Medical system in June and is currently working as an Advanced Hepatology

fellow at the same institution. Dr. Maddukuri has also studied Cell and Molecular Biology and Human Nutrition. He is interested in pursuing a fellowship in gastroenterology after his hepatology training. He would like to pursue a career in academic hepatology after completing his training. His interests include portal hypertension, TIPS, post-transplant complications and the porphyrias. In fact, he is currently involved in several porphyria related research projects with Dr. Bonkovsky. When he is not working and studying, he loves spending time with his daughter and enjoying his other interests -wildlife, history and politics. *Welcome Dr. Maddukuri!!!* We look forward to the years ahead with you as a porphyria expert.



Cemal Yazici, MD, who is also one of our new **Protect the Future** doctors, was born and raised in Istanbul, Turkey and graduated from Trakya University School of Medicine in Edirne, Turkey. After graduation, he moved to the United States in 2005 and finished his internship training in the Department of Surgery at St. Agnes Hospital in Baltimore followed by work at the University of Rochester as a postdoctoral fellow where he participated in the development of novel approaches to revitalize structural bone allografts. After completing his Internal Medicine residency training at Mercy Hospital and Medical Center in Chicago, during his residency, he worked as a research assistant in the Division of Digestive Diseases and Nutrition at Rush University. He realized that his passion was in Gastroenterology and Hepatology where his research interests became drug induced liver injury, microbiota and video capsule endoscopy. He joined Carolinas Medical Center (CMC) in Charlotte NC as a Hepatology Fellow to advance his clinical skills and research experience in the field of Hepatology. His mentor there is porphyria expert, Dr. Herbert Bonkovsky, who interested him in the porphyrias. Dr. Yazici says he is looking forward to gaining significant clinical experience in the evaluation and management of porphyria patients by working in the outpatient porphyria clinic at CMC and training as a PTF doctor. Dr. Yazici enjoys a host of awards and publications in his field and now is adding porphyria to his amazing skills. Dr. Yazici's parents and siblings live in Turkey, so he enjoys visiting them every year. His parents are from Tokat, Turkey which he considers the place of his roots. He enjoys soccer, his favorite sport, ethnic music, outdoor activities and cooking, a tradition that lies in his family. He is delighted to become an APF **Protect the Future** trainee and looks forward to doing his best for our community and patients. *Welcome Dr. Yazici !!!*

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Megan's School Speech "My name is Megan and I am in the Eighth grade. Just before I started kindergarten at SSA, I was diagnosed with a rare blood disorder called Erythropoietic Protoporphyrinemia (EPP) for short. It is one of the eight porphyrias. EPP is not contagious. It is something I was born with. In fact, both my brother, Riley, and I were born with this very rare disorder. There is a 50% chance we will pass it on to our own kids. Although Riley has been diagnosed with this same disorder, he does not seem to have the same intolerance to the sun as

I do. Many of you may wonder why I spend so much time at the lunch tables or in the office or in the classrooms helping the teachers instead of out on the playground with you. If you could feel my skin when it is exposed to direct sunlight, you would understand. When I'm out in the sun, the backs of my hands and face start to feel scratchy. If I stay out longer than I should, the scratchiness turns to a burning feeling that can last for days. It feels as though someone poured boiling hot water on my hands and face and takes days to get back to normal. The sun is not the only hazard with EPP. There is a chance that my liver can fail. In the past nine years, I've sometimes felt isolated from the students here at SSA. It wasn't anything you knowingly did. It just wasn't easy watching everyone heading out to the playground to have fun and having to stay back out of the sun. In Ms. Hoy's class, she arranged for a different pair of classmates to take turns staying with me at the lunch tables. Although I never made anyone stay with me, I appreciate their kindness and thank you for giving up your recess for me. Now that I'm heading to High School next year, I'm nervous as well as excited at what the future will be. I'm sure most of the students in High School won't have a clue about my condition and that suits me just fine."

The Power of YOU If you ever think that your efforts don't make a difference, you are wrong. For example, take a look at the video filmed by the FDA with two APF members, Matt Johnson and Mike Kenworthy and Dr. Robert Desnick. They enlightened the FDA and other health professionals on the severity of EPP and influenced their decision to move forward with Phase II clinical trials with Afamelanotide for EPP. To view the video, see: <http://www.fda.gov/ForIndustry/DevelopingProductsforRareDiseasesConditions/VideosPatientswithRareDiseasesandConditions/ucm266593.htm>

On the same FDA site, you can read the stories of Matt and Mike:

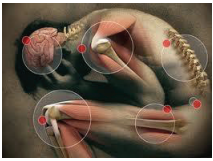
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Also, Mike and Steve Ferry and Mike Kenworthy attended an FDA event and convinced them to approve the Phase III clinical trials for SCENNESSE/afamelanotide. Then there is Dave McCrae, who single handedly changed the Washington state laws to favor people with EPP and severe photosensitivity, and Amy Chapman who began a one woman effort to teach doctors about porphyria, and all of you who demanded that Congress stop the 340B Hospital Budget expansion endangering rare disease treatment. SO if you ask, "WHAT CAN I DO?," please know, your every effort to promote porphyria awareness is important. Here are some suggestions. *First*, if you have EPP and want to help, see that the FDA understands the importance of having a treatment for EPP, please write the FDA explaining your need for a treatment ASAP and send your letters to the APF to take to the FDA. *Next*, please join the National Registry so we can prove to NIH that we have the numbers of patients to warrant their research funding. Signing up for the Patient Registry and the Longitudinal Study will help scientists answer important porphyria questions essential for further research. Also, help educate more future experts. For other suggestions, call the APF.



Medical Conventions As part of the APF physician education program, we attend and set up an exhibit booth at targeted medical conventions, in particular the *American Association for the Study of Liver Disease (AASLD)* and the *American Society of Hematology (ASH)* attended by approximately 8000 doctors each. These conventions are held in different cities each year, so members who live near where the convention is being held, man the exhibit booth and distribute the APF medical information about porphyria to the physicians, nurses and other healthcare professionals.

It is also a great way to enhance porphyria awareness and discover additional doctors who are or want to be knowledgeable about porphyria. Often physicians ask the patients who are in the booth to tell them about their own experience with porphyria. The most recent meetings were the AASLD meeting held in Boston, Nov 11-14 and the ASH meeting in Atlanta Dec 8-11. Elizabeth Sutton drove from her home in North Carolina to help us at the APF booth at the Atlanta ASH meeting and attend the patient meeting there. Thank you, Elizabeth, and Danielle Frazinni, Nathan Carr and Ellen Burrows who also helped us at the ASH. The conventions may be held near you next year. If so, you may want to help. It is an excellent learning experience for both you and the doctors. Don't forget-- If you want your doctor to receive a free information packet, like those distributed at medical conventions, please send the doctors name and contact information to the APF along with your name and type of porphyria.



Have You Ever Felt Like This? If so, you will be interested to know that the **APF Pain Program** is well underway. It is our mission to assure patients with porphyria that they will receive adequate pain treatment, because lawmakers, seeking to curb prescription-drug overdoses, fast-tracked legislation in some states to make it harder, if not impossible, for primary care doctors and emergency rooms to write prescriptions for large doses of opiate painkillers. Now, as

state regulators attempt to write the rules that doctors and other providers must follow, critics predict that making prescribing more difficult won't stem overdoses but will hurt patients with serious chronic pain. Some states have already initiated this new legislation that prevents ERs and primary care doctors from prescribing certain levels of pain medications to non-cancer patients. This legislation has greatly impacted porphyria patients since their own physicians can no longer treat their pain. Instead, they must be treated via Pain Clinics, which often takes weeks to receive an appointment and require a sizable down payment. The APF already has instituted a plan to expand this legislation to include porphyria through the following projects: approaching the individual state Health Departments; meeting with the most esteemed Pain Experts in the field, like Dr. Kathleen Foley who brought pain as a discipline to the medical field and professors in major medical schools, who advise and teach on the issue of pain and its unique problems. This is a serious problem for many suffering patients, one that deserves our full attention. If you have encountered an experience where you were denied treatment or were made to feel as if you were a "drug seeker," please contact the APF, ASAP!!!



Dr. Jeremy Latimer facilitated a meeting for Desiree with pain expert, Dr. Todd Gregory, at the Florida State Medical School in Tallahassee to gain from his expertise in the area of pain and medical government affairs. Dr. Gregory has a keen interest in the Porphyria Pain Program and will be providing input into the Pain Program as have other pain experts. Dr. Latimer will be part of the PTF program, as well as help with the pain project. He also kindly arranged a medical education presentation

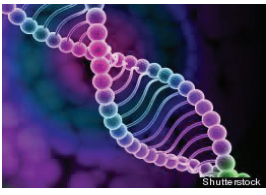
about porphyria in the Dominican Medical School with Dr. Anderson. *Thanks, Dr. Latimer!* We are very grateful for his interest in the porphyrias. (photo, Desiree & Dr. Latimer)

A Poignant Perspective It won't be long now for the trials with SCENESSE to be completed. Thereafter, all the data from the trials will be assessed and the FDA will make their decision to approve the drug. Patient volunteers have kept the APF abreast of how the treatment is working. We are grateful to all of the participants and in particular those who received the placebo. They got no benefit except to know that without them, the research would be of no value. T.S says, "I LOVE SCENESSE! Yesterday at noon I drove for an hour through the Texas sun in short sleeves to pick up one of our dogs and drove back and even stopped for a short errand, too. My arms & hands were completely in the sun the entire time! No pain! No reaction! I remember looking down at my left arm in the sunshine & thinking, 'This is what it feels like being just like everyone else in the world!' WOW! What will I do next year without it? Come on FDA! Praying for a compassionate FDA board to quickly approve this miracle! Praying everyone else is having a good experience with the implant, too!"



An AIP Experience "I'm Penelope Burris, a 31 year old from Missouri with AIP. Despite my ten years of illness, we didn't know I had AIP until I had a minor laparoscopy, 2002, followed by an acute attack which put me in the ICU. The doctors were stumped because the medications weren't making me better. When my mom researched my symptoms, she found porphyria and asked my doctor to do the 24 hour urine PBG. I was diagnosed with AIP and was given my first two PAN- HEMATIN treatments, which SAVED MY LIFE. I still have acute attacks, so when it was time for my third Panhematin, my doctor ordered a port at our local hospital. I was full of emotions. I was excited to

have the treatments but nervous and a little scared. Having my doctor arrange everything in advance helped the process go smoother. After I was admitted and in my room, the nurses prepped me for the procedure. Soon I was transferred to the surgical room for the port line to be inserted in my arm. Amazingly, I wasn't afraid. Once I was in the room, the team was already there and they were prepared for me, calm and friendly. In no time we began by putting the IV in to administer the numbing drug. The IV was the most painful part of the procedure, but very quickly the pain left. Once my vein was numb, the surgeon made a small incision in my arm and used a sonogram machine to guide the line. I felt no pain at all, but I did feel the port line going in. He checked on me and asked me if I wanted to watch the machine, but I declined - I was just wanted it over quickly. My mom was able to be right there with me and it was a comfort. Before I knew it, it was over and I was ready to receive my Panhematin treatment. Back in my room, I received my treatment over a three day period. Although I could move my arm, I decided against moving it around at all during the treatments to minimize damage. I felt better almost immediately after my Panhematin treatment began. Despite some phlebitis, inflammation and weakness in my arm, it was worth it because the Panhematin treatments have helped to control my AIP."

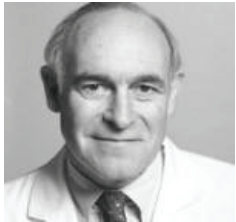


Storing Information on DNA When it comes to storing information, hard drives don't hold a candle to DNA. Our genetic code packs billions of gigabytes into a single gram. A mere milligram of the molecule could encode the complete text of every book in the Library of Congress and have plenty of room to spare. All of this has been mostly theoretical—until now. In a new study, researchers stored an entire genetics textbook in less than a picogram of DNA—one trillionth of a gram—an advance that could revolutionize our ability to save data. A

few teams have tried to write data into the genomes of living cells, but the approach has disadvantages. First, cells die—not a good way to lose your term paper. They also replicate, introducing new mutations over time that can change the data. To get around these problems, a team led by George Church, a synthetic biologist at Harvard Medical School in Boston, created a DNA information-archiving system that uses no cells at all. Instead, an inkjet printer embeds short fragments of chemically synthesized DNA onto the surface of a tiny glass chip. To encode a digital file, researchers divide it into tiny blocks of data and convert the data not into the 1s and 0s of typical digital storage media, but rather into DNA's four-letter alphabet of As, Cs, Gs, and Ts. Each DNA fragment also contains a digital "barcode" that records its location in the original file. Reading the data requires a DNA sequencer and a computer to reassemble all of the fragments in order and convert them back into digital format. The computer also corrects for errors; each block of data is replicated thousands of times so that any chance glitch can be identified and fixed by comparing it to the other copies. To demonstrate its system in action, the team used the DNA chips to encode a genetics book co-authored by Church. It worked. After converting the book into DNA and translating it back into digital form, the team's system had a raw error rate of only two errors per million bits, amounting to a few single-letter typos. That is on par with DVDs and far better than magnetic hard drives. Because of their tiny size, DNA chips are now the storage medium with the highest known information density, researchers report online today in "**Science**."

Robert J. Desnick, M.D., Ph.D. Congratulations to the new Dean for Genetics and Genomic Sciences;

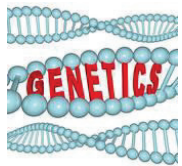
Professor, Genetics and Genomic Sciences; Professor Pediatrics, Oncological Sciences, Obstetrics, Gynecology and



Reproductive Science and Gene and Cell Medicine, Mount Sinai School of Medicine, New York City. Dr. Robert Desnick has published over 600 research papers and chapters and has edited nine books. He is an elected Fellow of the American Academy for the Advancement of Science and an elected member of the Institute of Medicine of the National Academy of Sciences. Like his publications, his awards are also too numerous to list. Mainly, he has been a friend and APF Scientific Advisory Board member for over 30 years, as well as Co-Director of the Porphyrin Research Consortium. We are very grateful to have such a prestigious physician on our board

and congratulate him as the new *Dean for Genetics and Genome Sciences*.

See; <http://www.mountsinai.org/profiles/robert-j-desnick>



News in the Gene World

1: GENE THERAPY PENDING APPROVAL *The European Medicines Agency (EMA)* announced impending first approval of a gene therapy in the western world. It is for lipoprotein lipase deficiency (LPLD), which is an ultra rare disease causing episodes of very painful pancreatitis that can be fatal

2: FINDING HOMES FOR STALLED DRUGS Researchers can now submit pre-applications to the *National Center for Advancing Translational Sciences (NCATS) Discovering New Therapeutic Uses for Existing Molecules* program. The idea is simple yet brilliant: match compounds that are languishing on company shelves to diseases with newly-discovered mechanisms.

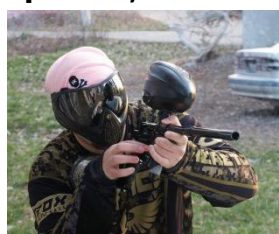
3: SPEEDING FDA APPROVAL When the *FDA Safety and Innovation Act*, which updates the 1983 Orphan Drug Act, was signed into law, it provides \$6 billion over the next 5 years to assist the agency in evaluating new drugs and medical devices. The Act will speed access to new treatments and development of especially promising ones. The Humanitarian Use Devices program will target those that treat rare diseases with children as the priority.

4: EASING INSURANCE ACCESS When the Supreme Court upheld the *Affordable Care Act* on June 28, people will not be penalized for their pre-existing conditions, nor face annual or lifetime insurance caps.

5: IDENTIFYING DISEASE GENES Exome sequencing can identify mutations when single-gene tests don't. The strategy sequences the protein-encoding part of the human genome in individuals, usually young children, whose syndrome has evaded recognition, searching for mutations passed silently from parents, with functions that could explain the symptoms. Once that is known, researchers can develop new treatments or repurpose existing ones.

**Did you know that the APF has over 5000 members and 2000 doctors interested in porphyria?
And the APF has the most active *Scientific Advisory Board* of experts than any other rare disease**

Paintball for Porphyria



APF member, Dan Yelen, put the FUN in FUNdraising by hosting a **Paintball Explosion**, in Dundee, Illinois on November 4. Dan's friends in the paintball community, as well as porphyria patients families and friends from around the state gathered to watch and participate as the paintballs started flying—making the day a great success. Dan and the APF send a special thanks to TJ Andres for providing the field, hosting the event and donating items, including free admission passes for the field. Also, thank you to the Saints Paintball team for helping Dan advertise the event, as well as Dan's team mates, The Chicago Heretics. Valken Paintball, Nicole Kinner, Matt "Leo" Osborn and Aurora Oil & Lube, Punishers Paintball, Lapco Paintball, The Chicago History Museum, and Zach Fusco also deserve our thanks for supporting the event, donating

raffle items and helping it run it smoothly. Thank you to the guests who played and also to those who participated in the raffle. Together they raised over \$850 dollars through the raffle alone and are awaiting the total donation to the APF. Dan tells us that the **Porphyria Paintball Explosion** has already been OKed for next year and that he is thinking about how to make it a bigger and better! Here is how he got involved, "I have Acute Intermittent Porphyria, AIP, that causes me intermittent bouts of extreme abdominal pain, limb numbness, fatigue, delusions and other symptoms. It is a hereditary disease that I received from my mother, who suffers from it worse than I do. She receives treatment monthly with Panhematin, the only drug treatment for acute porphyria. Because this is a rare, hereditary disease, all funding for the disease's research and public awareness comes mostly from the pockets of private donors. Funds are limited for the American Porphyria Foundation, too, so, I have taken upon myself to ask for assistance from the paintball industry, the industry I know and love."



Boston Patient Meeting

The APF and renowned porphyria specialist, *Dr. Peter Tishler*, hosted a patient meeting November 12 at Brigham and Women's Hospital in Boston where Dr. Tishler maintains a genetic clinic and laboratory. Dr. Tishler made an exceptional presentation on each of the porphyrias, as well as his research and the compilation and maintenance of the safe and unsafe drug list. Also participating was expert, *Dr. Herbert Bonkovsky* from the Carolinas HealthCare Systems. Dr. Bonkovsky gave an overview of the Porphyria Research Consortium, the National Registry, and their research, including the Longitudinal Study. Both physicians answered an array of pertinent questions from the attendees, who also shared their own experiences with the disease. Learning from an expert helps demystify and clarify much of the misinformation that is so prevalent about porphyria. The meeting was held in conjunction with the *American Society for the Study of Liver Disease* (AASLD), a medical convention attended by about 8000 physicians and health care professionals.

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Jamie Russo

"My parents knew something was wrong at about age two. We were in Florida for vacation. I guess it was in the evening of the first day, I woke from a nap and my mother says my face was so swollen she could not even recognize me. That was the start of many doctors' appointments. My mother was told repeatedly that I had Lupus until we found a doctor who knew exactly what was wrong with me when I was six. The recommendation was and is always the same, 'Stay out of the sun.' Over the years, I have tried to learn my tolerance (impossible!!!), so I do suffer terribly at least once a year. At fourteen, I desperately wanted to make friends, so I went with a girlfriend to a water park (Big Mistake!). After being in the sun all day, I returned home with my feet



so swollen I thought they would bust!! I spent three days awake and soaking them in buckets of ice water. I don't use this method anymore. After the three days, my mother took me to the ER, where they thought I had broken my ankles. We tried to explain the EPP and got looks like we were crazy. They gave me a shot of cortisone and sent me home. After years of battling this disease and just wanting to be like everyone else, I have adjusted to being a night owl and living life backwards. My mother has been great. She would let me stay outside at night, run through sprinklers at night, or whatever I wanted to do. So, as an adult, I work during daylight hours and stay up all night. It is always hard because people don't understand EPP. The one thing that sends me into fits is when they say, 'Just put on some sunscreen.' GRRRR that doesn't work!!!"

APF WARNING CARD FOR ACUTE PORPHYRIAS If you have an acute porphyria and have never received a **Warning Card** for your wallet from the APF, contact Yvette at the APF and she will send one, free, to our members. The Warning Card notes that you have an acute porphyria and how to access the APF, the APF website and the Safe and Unsafe drug list. Please contact Yvette at porphyrus@aol.com or call the APF office at 713.266.9617.

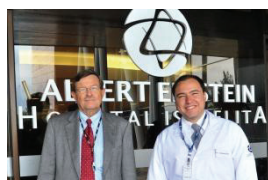
Your Help is Needed for the Longitudinal Study



Consortium Research updates: One of the Consortium researchers goals is the project, "Identification of Biochemical Features That May Predict Which Patients Will Become Symptomatic." With the help of the American Porphyria Foundation, they are actively recruiting patients with the acute porphyrias who have frequent attacks. These cell lines and DNAs will allow the Consortium researchers to look at the differences between these patients and their heterozygous, but latent, siblings and/or unrelated heterozygotes, who are latent for such attacks. Also, they have performed an analysis of the biomarkers in the AIP mice to see if they could identify metabolic markers for an acute attack. These data are being analyzed and then patients will be analyzed for candidate metabolites. In addition, the Consortium is assessing "Study Materials for Future Investigations." They have an approved repository and are collecting DNAs and cells when available from our well characterized patients. This effort will continue to expand the IRB approved Repository. In summary, efforts in the next two years will focus on collecting longitudinal data and increasing our numbers of well documented patients. They also will focus on publications based on the data that have been accrued in the next year. The researchers very much need more porphyria patients to enroll in the Longitudinal Study by first enlisting themselves on the National Registry so the researchers can contact you directly. It is so important to join the National Registry, <http://rarediseasesnetwork.epi.usf.edu/registry/direct.htm>. Find your type of porphyria and follow directions.

Ask the Experts

If you have Questions, just mail or email them to our "Ask the Experts" at Lyonapf@aol.com and note "porphyria" in the subject line. **Question From SD, GA.** "When I did my urine PBG, I was given a brown bottle to keep the sample from the light and was told to keep it refrigerated, but it did not contain a preservative. Will the test be ruined since there were no preservatives in the sample bottle I used for the PBG and ALA urine test?" Dr. Karl Anderson answered, "Since we measure ALA and PBG on the same sample, it's best to use sodium carbonate only – Na₂CO₃. No acetic acid is used, unless one is going to measure only ALA, which is almost never indicated! A preservative is only needed for a 24 hour urine, and even then, it is not absolutely essential."

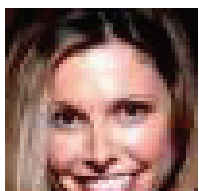


Photos L-R, DeLima & Anderson view records & with patient,

Anderson & Perini at Einstein Hospital & with patient,

Anderson & Lourenco

Brazil As part of the Brazilian PTF program, Dr. Karl Anderson recently travelled to Curitiba, Sao Paulo and Rio in a cooperative effort with their three outstanding Protect the Future Doctors, Drs. Angelica DeLima in Rio, Charles Lourenco in Curitiba and Guiherme Perini in Sao Paulo. Dr. Anderson made presentations in their hospitals about porphyria to physicians and patients, as well as consulted with the PTF doctors and their patients. Promoting porphyria awareness and education was also one of the major targets of Dr. Anderson's mission. A three city series of seminars in six days was quite an undertaking, so thank Dr. Anderson and the three PTF doctors in Brazil for facilitating these meetings. We also want to thank Ieda Bussman for arranging the Curitiba meeting and the donors who made these meetings possible. We are proud that the APF-PTF program has become a model for organizations around the world. We are also proud of Drs. DeLima, Perini and Lourenco who are Brazil's future porphyria experts. *Editor's note: Dr. Anderson also recently spoke to medical students at a medical school in Dominica.*



Ariel Lager knows the ropes and isn't hesitant to tell the Emergency Room Team to read the ER guidelines. She gained this experience through her many trips to the ER near her Pennsylvania home during many AIP attacks. Over time, she has learned how to deal with ER visits and tells them immediately about her porphyria and what her doctors concur she needs. According to Ariel, "I've been through this before, so I usually am very vocal about what I need and getting it started. I've learned from experience to do this because sometimes to get orders takes forever. By the time

I make it in to the ER, I have already been in extreme pain, so I need help ASAP. I tell them about Panhematin, how I take it, and how to put it in the orders. Because I have done this so often, I am firm in expressing the needs my doctor and I have developed to help me through an attack. When they want to give me something I can't take, I ask to speak with the ER Chief Attending Physician and Nurse in charge."

Fortunately, Ariel's father is a pharmacist and knows how to mix the Panhematin treatment properly, including adding Albumin as suggested by porphyria experts. Still, she has problems with medication. Unfortunately, these same issues are increasing in ER's around the country, particularly in the area of pain management and treatment.

FACEBOOK and Twitter and the APF Blog, *Purple Light*. If you enjoy social networking, join one of the APF's five FACEBOOK groups. Communicate with people who have your type of porphyria and hear their experiences while sharing your own. We have approximately 1000 FACEBOOK members now in these five groups. You can be in an open group for all to see and share, and four closed groups as follows: an AIP, VP, HCP, ALAD group; an EPP group; a PCT group and one called *26 Below* for young people below age 26. The closed group means you must join the group to view what is being shared with the other members and to place your own posts. This option is an excellent mean of protecting your privacy. Don't forget to sign up for Twitter and the *Purple Light Blog*. If anyone is interested in sharing their experiences on the Blog, contact Amy Chapman at: Amychapman1992@gmail.com.

Thanks! Monica Fleegle was keenly aware that timing is of great importance during the EPP clinical trials, so when her plane was grounded during the recent storms, she got busy. Southwest Airline provided her with a hotel to help her still make it to University of Alabama to complete the stringent time requirements. The UAB research team rescheduled all of her appointments and Monica made it despite all odds against her. Thanks Monica for being such a dedicated volunteer. It takes dedicated volunteers like Monica to complete the trials and gain a new treatment. *Thanks!!!*



Lyon's Share Important to each of you is that on the APF website, there is a *Patient Registry*, where patients can ask to be contacted by the experts and their team for information about prospective studies or other related needs. Each of you can be of great help by registering on this Registry. The Registry is also important because the numbers signed up are indicators to the government that there are enough patient to warrant them providing research funding. In other words, at the moment we only have 600+ people registered on the Registry, yet we have 5000 APF members. It would help considerably if our numbers on the Registry were greater. Then when we go to the NIH and request funding, we can point to the numbers of people on the Registry with assurance. Another important reason to join the Registry is that the scientist can determine porphyria incidence. We are always asked, "How many people have porphyria?" Your participation will help us *finally* answer that question.

<http://www.porphyrifoundation.com/get-involved/join-the-registry>

Since we are at the end of our 30th Anniversary year, I want to thank you for 30 years together. I have met and spoken with over 16,000 people, which was enlightening and gratifying.

Coping Tip 101 APF member, Denise Phillips, has a great way to lessen the trouble of porphyria in her life. She created her own "I'm Thankful Book" and put it on the nightstand by her bed. Every night before Denise goes to sleep, she fills the "I'm Thankful Book" with the things for which she was grateful for that day. She says it helps her get her life in perspective and enlarges her capacity to live in gratitude despite her health troubles. Hers is a good suggestion for all of us to help us acknowledge our blessings in the face of our troubles with porphyria. Denise, we're thankful for members like you! If you have a good coping tip, please send it to the APF for the newsletter.

Atlanta Patient Meeting was held December 8, 2012 at the Hampton Inn Atlanta-Buckhead. More such meetings like the one in Atlanta, San Francisco and Boston will be held around the country. They are not only a great learning experience, but they're a fun way of meeting other patients and getting your questions answered by an expert. Thanks to esteemed porphyria scientist, Dr. John Phillips, from the University of Utah in Salt Lake City, who made an outstanding presentation enjoyed by all. Dr. Phillips is also one of the members of the Research Consortium and a Principle Investigator in the EPP Clinical Trials. Watch your Enews for the announcements of the meetings and contact the APF to let us know you want to participate.



Loving Gifts We are saddened to hear of the passing of dear family members and friends. Some of you have chosen to honor their lives by making a gift to the APF to help others with porphyria. Please join us in thanking: Genevieve H Rose for **Terri Easterwood**, Doris A Brehm for **Gerald Brehm**, Mary P Crown for **Dean Puccia** and **Mary Blanch Hargett**, Ralph M Gray for **Fred L Gray**, Kim B Watkoske and family for **Damien Buchkowski**, Mt. Zion Baptist Sr. Sunday School for **Evelyn Tilgham**, Joseph Weller for **Charlene Weller**.



We also thank those who donated to the APF in honor of a friend or family member. Sharon I Koch for **Jagger** and **Jake**, Eli Cohen for **Dr. Robert J Desnick**, Desiree for the **APF Scientific Advisory Board and the APF staff, Carol Hughes, Yvette Strange, Elizabeth Pettit, Alexis Lockwood, Maria Gonzalez** and the FACEBOOK volunteer administrators, **Amy Chapman, Victor Mejias** and **Rob Saupe**.



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

Is Your Membership Up to Date? The APF is able to maintain our physician and patient education programs and many other services because of your support. We do not receive government funding to run the APF, rather we receive donations from you, your friends, your family and people interested in the porphyrias. Now we need your support for several programs that are very special.

First, our **Protect the Future** program to train future experts is important to our future health. Without experts, our primary doctors have nowhere to turn for advice and to learn about porphyria. This is a serious problem that we are trying to prevent by training young doctors, but we need your help funding this program.

We also have an enormous physician education program that distributes exceptional educational materials to doctors. Please help us produce these materials.

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