AMERICAN PORPHYRIA FOUNDATION

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What's New at the APF

www.porphyriafoundation.com

Updated Member Stories Section: Find full-length versions of the member stories in this issue of the newsletter, and several more new ones.

Be sure your doctor knows about the **Drug Safety Database for Acute Porphyria** at www.apfdrugdatabase.com/ and remember to join the National Registry so you can be counted!!!

Is Your Membership Up to Date? Stay current on all the latest news about testing, treatment, and member meetings in your area! Please take a moment to renew at our website, or call us at the office: 1.713.266.9617 or 1.866.APF.3635.

The Emergency Room Kits have been upated and expanded. This is the best money you have ever spent. Also an APF DV porphyria live and get one free for your doctor.

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AMERICAN PORPHYRIA FOUNDATION

1st Quarter, 2011

Porphyria Awareness Week April 16-23, 2011

The challenge of living with a rare disease starts with how little is known about it—among friends and family and in the medical community. Raising porphyria awareness is about improving the quality of your life through greater understanding, increasing the chances of prompt diagnosis and improving your access to the right medical care. **National Porphyria Awareness Week** provides **YOU** with the opportunity to help the public and medical professionals in your community more readily recognize the need for better diagnosis and treat-ment of porphyria. Since many of **YOU** have asked for suggestions to accomplish this important mission, we have provided the following list. We also have many materials to assist **YOU** in this important mission; Fact sheets, Posters, Brochures, Overviews, DVD's etc.

How You Can Help

TELL your story to local media. Television, newspapers, community magazines are looking for human interest stories about people in their community who have encountered a major illness and undertaken the challenge to help others in a similar situation. Remember Cason and Caul, sons of Lee Ann and Chris Cook, whose EPP story warranted a full page in their local newspaper.

SHARE knowledge about porphyria at your doctor's offices and local hospitals. You might suggest that they host a seminar or grand rounds on porphyria. Some members have even set up an information table or exhibit at a health fair. Give your doctors a DVD or tell them about the free CME courses on the acute porphyrias for their continuing medical education. Think of Amy Chapman who has been sharing her porphyria story to various doctors groups in her city and others states.

VOLUNTEER your talents and skills, like computer expertise, business acumen or other skills to help achieve the educational programs of the APF. Our talents are varied and plentiful and can be used to help one another. For example, you might donate one of your paintings, sculpture, weaving, etc.

HOLD a community race, car wash or other fund raising activity to support research or an APF program of our choice, Physician Education, Patient Education, Protect the Future program to train the next generation of experts. Remember Parker Snyder, our youngest fundraiser, who distributed porphyria information at his wrestling match or our Ironman, James True, who raced for porphyria.

ENCOURAGE your doctor to present a seminar on porphyria using the Power Point Presentation on the website. Many APF members have told their doctors about the free Continuing Education Course (CME) and they have taken it.

Already On The Calendar For Porphyria Awareness Week And Beyond:

- **Margarita Cianchini** has been approaching the Latin Radio Stations about running PSA's to promote porphyria awareness.
- **Kate King** is encouraging local television stations to donate airtime for a porphyria PSA.
- **Annie Pangle** is arranging the next Conference call with an expert to take place near Awareness week. TBA.
- **Janie Williams** is getting her story to the local news media and hopes to propel it further
- **Joanna Floyd** is attending Health Fairs and send-ing emails re: porphyria awareness to PA hospitals and is getting great response.
- **Sherilyn**, an outstanding nurse in North Carolina requested the DVD, brochures, the doctor kit, the ER patient kit, the Warning Card, and other educational tools. She has arranged many events.
- **Amy Chapman** has arranged a series of meeting with physicians to discuss her case as a physician outreach effort.
- **Lisa Kancsar** has been very successful with her medical education efforts.
- **Nathan Carr**'s hospital is placing porphyria materials in their library and sending email reminders about the materials at Nathan's behest.
- **Jill Gould** and her mother are writing a book about Jill's experiences with porphyria.
- Our social networking attempting to gain higher exposure on the internet.
- **Facebook** group members have been terrific at promoting porphyria and encouraging each other.

It's not too late to plan your own event with the American Porphyria Foundation! Remember we will give you the supplies you need to host a great and event. For details on any of the activities listed here or for help planning your own, please contact us Toll Free at:

1 866-APF-3635 or email us at porphyrus@aol.com

HOUSE MD likes Porphyria. The HOUSE television series has aired nine programs that feature porphyria. The most recent HOUSE episode highlighted a patient who was diagnosed with acute porphyria and was finally given heme therapy (Panhematin) treatment after a series of frightful misdiagnoses. Dr. House, who is played by Hugh Lauri, is an antisocial maverick doctor who specializes in diagnostic medicine and does whatever it takes to solve puzzling cases using his crack team of doctors and his wits.

Another such medical program, **GRAY'S ANATOMY**, also included a story of a patient with porphyria who suffered from the pain of the disease and was eventually treated with Panhematin to abate the patient's attack. Unfortunately, many patients do not have the luxury of having a doctor know how to diagnose or treat porphyria. Interestingly, these television programs enhance awareness of the disease and even present treatment options. We sincerely appreciate the producers who use porphyria in their series. Even the recent blockbuster movie, THE KING'S SPEECH, credited the American Porphyria Foundation for their assistance as we did for the movie, MADNESS OF KING GEORGE.

The APF has a very active media campaign for television, film and print media to promote porphyria, and we have enjoyed amazing results. The most important end result is that patients across the country were diagnosed with the disease and treated.

The following is a list of programs which also have featured porphyria or a patient with porphyria:

- **House**, Honeymoon, Season 1: episode 22
- **House**, Fools for Love, Season 3: episode 5
- **House**, Finding Judas, Season 3: episode 9
- **House**, Don't ever Change, Season 4: episode 12
- **House**, Guardian Angels, Season 4: episode 4
- **House**, Whatever it takes, Season 4: episode 6
- **House**, Itch, Season 5: Episode 7
- **House**, Emancipation, Season 5: episode 8
- **House**, Let them eat cake, Season 5: Episode 10
- **Gray's Anatomy**, Time Warp Season 6 episode 15
- **Castle**, Vampire Weekend, Season 2 , Episode 6
- **Scrubs**, My Ocardial Infarction: Season 4, Episode 13
- **Scrubs**, Kelso's last stand,Season7: episode 9
- **Scrubs**, My Dumb Luck, Season 9: episode 7
- **Scrubs**, Outta here like Vladimir: Season 8, Episode 4
- **CSI Las Vegas**, Justice Served Season 1 Episode 21
- **CSI Las Angles**, Once Bitten , Twice Damned Season 2
- **ABC News Specials**, Medical Mysteries Series, episode 2*
- **ABC News**, Desiree Lyon interview
- **ABC Prime Time**, CEP segment
- **Mystery Diagnosis**, The Sickest Patient in the Hospital and Terrifying Tremors, Season 5
- **Mystery Diagnosis**, The Boy Who Kept Swelling, Season 6 episode 6
- **Mystery ER**, Seeping through the cracks/Purple Haze, Sea-son 1: episode 3
- **Secret History**, Purple Secret in Search of Royal Madness, Season 6: episode 6
- **Montel Williams**, Porphyria with Lauren Warren
- **Montel Williams**, Rare Diseases, Leppert Family
- **Travel Channel**, Documentary Romania
- **Learning Channel**, Dec 09 Porphyria, another myth in the making.
- **Fox News**, Desiree Lyon interview
- **Fox News**, Vampires, A Medical Myth Nov 2009
- **Fox News**, King George, Madness or Arsenic July 2005
- **BBC News**, Desiree Lyon
- **Sanjay Gupta**, CEP patient, Kasey Knauf CEP
- **Anderson Cooper 360**, CEP
- **CNN**, documentary on CEP patient, Kasey Knauf
- **CNN**, interview Desiree Lyon (CNN HERO)
- **Dr. Oz**, EPP patient, Craig Leppert
- **National Geographic**, Feb 2010 Six Ways to Stop A Vam-pire
- **Court TV**

PANHEMATIN

For those of you who have asked about the Panhematin treatment for acute porphyrias, information about the treatment is available on the APF website www.porophyriafoundaiton.com If you want your doctor to receive a very comprehensive packet of information on the diagnosis and treatment of acute porphyrias (AIP, VP, HCP), you can contact the APF and give us your doctor's name and address. We will send a packet immediately and add your doctor to our database, as well as update him/her on any research or treatment news through our quarterly physician updates. If you would like us to send a *Panhematin* brochure or a *Management of Acute Porphyrias* to your physician or a *Physician Kit*, please send your doctor's contact information.

In fact, if you want to receive updates about porphyria, please contact the APF with your email address. We will add you to the internet ENEWs along with your doctor.

REMEMBER — Your Donations Support — research, physician and patient educational materials and programs, training future experts, national and local media campaigns to enhance porphyria awareness, newsletters and website, and a host of services for patients.

Janie Williams

I always felt my personal story was so private that it was "my secret." However, it is now time to tell it in hopes it will help others. As a young woman, I always had abdominal pain, which we referred to as "the Arrington stomach," because my family had stomach problems all their lives. No matter how many times I told doctors, they said it was nothing even though sometimes the abdominal pain was so fierce I wondered if I should pray for death. I was sent home from the hospital repeatedly. In my 20's, I continued to sunbath and drink socially, which are two of the biggest 'no-no's' for this disease.

At age 29, after sunning, my urine was the color of 'brick red.' I had blisters on the back of my hands and on the end of my toes. The pain was so fierce I could not even wear shoes. On a hot day, I would feel like my skin was on fire and itched so much that it felt like it was unzipping. By then, I had been to 11 doctors and decided to try a dermatologist. He took one look at me and said I had a rare genetic disease called Porphyria and promptly sent me to the University of Southern California which at that time studied Porphyria. I learned how to avoid these attacks by eliminating alcohol and using very smart judgment about the sun during the eight hottest months of the year, wearing sun protective clothing, and playing golf very early in the morning.

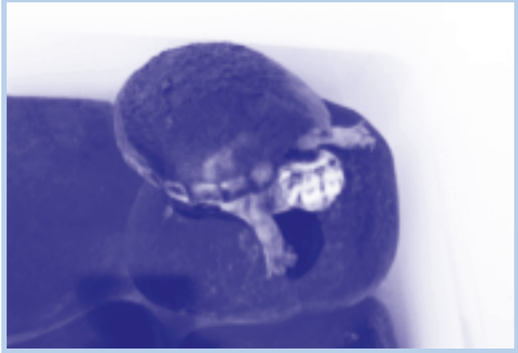
I began to study nutrition to save my own life, however, it was through the American Porphyria Foundation that I received the most education to understand this disease. For a person with porphyria, the quality of one's life is being able understand what is going on and to be able to avoid attacks. Right now, I am living my American Dream of feeling as GREAT as possible everyday and enjoying life to the fullest. It is definitely a full time job being diligent to avoid Porphyria attacks, gain knowledge, and live a normal life because I deserve it, and so do my husband, family and friends.

Alie Campbell

Longtime APF member, Alie Campbell, serves on the APF patient advisory committee, so she is sensitive to issues that are relative to people with porphyria. Recently, Alie encountered a problem in an Emergency Room that she felt was important to other patients. Fortunately, several of our experts will be involved with an ER Imitative to help patients receive appropriate help when they arrive in an ER. Allie's story follows:

To help other people, I need to share an experience I had at the hospital when I endured lung damage from a fire at my home. As we all know, emergency rooms are often filled with people who have the non-life threatening illnesses, which apparently is a source of great stress for the hospital staff. When I was finally taken back to be exam-ined and had answered the initial information, I presented them with a copy of APF drug guidelines-safe and unsafe. This should have been in my records with them but it never is and I don't understand WHY. I have been told it is just too much information to enter.

What was bizarre was the following exchange with the Emergency Room nurse. She looked at the list and said, (I paraphrase) "Thanks for the list, but if you haven't actually taken all of the unsafe drugs then you don't know if they are dangerous or not. So, I would think that this information is just a generality. You will have to take the meds to know for sure!" When I heard her say this, I sat there in utter disbelief, trying to understand how or even why she would make this statement. I wondered if she would be willing to give a couple of pounds of sugar to a diabetic? Or dillantin to a person that doesn't have epilepsy...just to see!!! We need to address such an attitude. Thanks again for all the work you and the APF staff do on o of those of us who have a "porphyria"!



Remember the Alamo

If you remember our turtle friend, Alamo, then you have been a longtime member of the APF, because he was 23 years old on March 9, 2011. Alamo has been a member of the APF since she was a baby and was the only non-human member of the APF for twenty years. It wasn't until Alamo lay eggs that her parents, Claire and Robert Sadowniczak of Orlando, Florida discovered he was a she.

The APF wants to wish Alamo a very
Happy 23rd Birthday

Porphyrins and Porphyrias International Conference 2011: Cardiff, Wales

The Porphyrins and Porphyrias International Conference, which will be held in Cardiff, Wales April 10-14, 2011, will include an international patient meeting on April 14. The scientific portion for Porphyrins and Porphyrias 2011 will aim to cover the latest developments in the field of heme-related disorders. The meeting will include plenary sessions with invited speakers, free Communications and poster presentations. As with previous Porphyrins and Porphyrias meetings, there will be contributions from the diverse range of professions working in the field including laboratory scientists, clinicians, molecular biologists, laboratory and clinical academics. Following the scientific portion of the meeting, there will be a patient meeting on April 14 hosted by the British Porphyria Association. Desiree Lyon Howe will be one of the speakers at the patient meeting. If any APF members plan on attending the conference, please let us know so we can arrange a "meet and greet." This is a wonderful opportunity to make new friendships with people with porphyria around the world.

The experts will have the opportunity to visit with their international colleagues with whom they have collabo-rated for thirty years, as well as meet the new doctors who have taken on porphyria as a field of interest. Dr. Herbert Bonkovsky from the Carolinas Healthcare System in Charlotte will make the first presentation of the meeting on the Acute Porphyrias. Dr. John Phillips from the University of Utah will also be speaking.

The American Porphyria Foundation is supporting the travel so that our *Protect the Future* doctors as part of their training. They are joining their US colleagues to meet other experts around the world. Our Brazilian trainees, Dr. Guiherme Perini, and Dr. Charles Lourenco, will be attending, as will a number of our other *Protect the Future* doctors. This is an exciting opportunity for them to meet their international counterparts and a challenging educational experience to enhance their porphyria expertise.

Protect The Future (PTF)

We are proud to welcome Dr. Maged Kadry Rizk into our PTF program. His first PTF training experience will be the International Porphyria Conference in Cardiff. Dr. Rizk, who practices at the Cleveland Clinic, in Cleveland, Ohio, earned his Bachelor's of Science and Medical Degree at Wayne State University School of Medicine. He was a fellow in Gastroenterology and Hepatology at the University of Iowa Hospitals and Clinics and a Resident in Internal Medicine at the University of Illinois Hospital-Chicago and his Internship at the University of Illinois Hospital-Chicago. Dr. Rizk has a distinguished list of awards and publications, as well as a mission award for his work in south Africa, Zimbabwe, Zambia.

Dr Rizk is a key participant in an upcoming Emergency Room Imitative, which will assist ER physicians to recognize an attack of acute porphyria and educate them on how best to treat patients who are in an attack. Dr. Rizk is quite knowledgeable about porphyria and is seeking to broaden his expertise in the field. He is looking forward to training with the best experts in the country and will begin with the conference in Cardiff. Dr. Rizk will then join Dr. Karl Anderson for a special Porphyria Week to be held in Galveston this spring.

PROTECT THE FUTURE (PTF)

The PTF program is one of the most important in the APF. As our present experts retire, we must educate the next generation of experts. Our Consortium of experts and re-searchers have joined with the APF to take on this challenge by training a group of young doctors to become the future experts. We are proud that we have an outstanding group of future experts in training. These doctors are the "best of the best" in their fields, who are training with the "best of the best" of porphyria experts. But we cannot achieve this without funding. Please consider your part in Protecting Your Future and that of your children and families since Porphyria is a genetic disease. Please make a donation to the **Protect the Future** program to support this outstanding project.

We are so fortunate that one of members has made a $100,000 matching grant, which has been matched!!! However, this training is very costly so we need your help to train Drs. Balwani, Liu, Singal, Mittal, Lee, Lourenco, Wicklliff, Perini, Narang , Thapar, Sood, Freilich, Parker, Guy, Wang, and our latest Dr. Rizk.

To donate to this program, please mark your donation - PTF. *Thank You!!*

Canadian Collaboration

An exciting collaborative event took place in Alberta, Canada with the Network of Rare Blood Disorder Organizations. They held a conference on March 4-5, 2011 at the Hematology Department of the University of Alberta. The network, which includes the Alberta Porphyria Association responded to the needs of patients around Canada.

The Main Event included sessions dealing with topics that appeal to patients, family members, caregivers and the general public. The entire event was FREE and gave everyone the opportunity to meet and interact with physicians and health care pro-viders who work with blood disorders on a day to day basis. The attendees had the chance to meet and network with others who were directly affected by their respective diseases.

This was particularly important to porphyria patients as the Canadian Porphyria Foundation had to close it's door due to funding problems. Let's hope our members continue to support the APF, as our members are our major means to enhance education and awareness efforts. If you would like more information about the meeting and/or the potential formation of a pophyria organization in Canada, please contact the Alberta group at albertaporphyria@gmail.com.

We are the Much More

APF member, Susie O'Berski, has written a warm, wonderful, challenging and encouraging book, ***We are the Much More***. She includes an episode about her bouts with Hereditary Coproporphyria (HCP), relating how she was diagnosed and treated. ***We are the Much More*** is a book on faith and the joy that her faith has brought her and her family. Susie shares her faith, family, friends and fun in her story.

If you have written a book or article, please share news of your creation with the APF. Our members enjoy hearing about and reading the work of other people with porphyria.

We would love to see your paintings, photographs, gardening or any other handiwork. We are a creative group. *Many thanks.*

FAITH
FAMILY
FRIENDS
FUN

In Memory

When our friends pass, we are very saddened because many of them have be-come dear friends. Some of their loved ones have chosen to honor their life by making a gift to the APF. Please join us in thanking:

Helen and Donald Herman, Barbara and Dwight Meyer, Mary S. Sauerteig, Kathleen and John Howell, Nancy L. Grahma-Myers for ***Laurie E. Breier***; Donna and Richard Coffey, Susan and James Evans, Joan and Robin Brown, C. Gayle Mitchell, Myrna Levy for ***Dorothy Simko***; Kathleen and Robert Clausing, Village of Hortonville, Bill Fermanich, Patricia A. Ratzlaff, Paul D. Baumgart, Mike Huzzar, Blankenheim Services, Debbie and William Fermaich, Trisha J. Gavin, Carole and Daniel Laird, Laura Newhouse, Daen and Stephen Roder, SaraLee for ***Hildegarde Fermanich***; Nita Busby for ***William Frederic Petrunio***; Elaine and Thomas Smuczynski for the ***Smuczynski Family***; Darby and Paul Busse for ***Vivienne R. Busse***; Joe L. Yager for ***Arlene J. Yager***; Gary R. Horn for ***Sandra Horn***; Dolores M. Brazas for ***Wesley J. Brazas***; Dr. Susan L. Engel for ***Lee Engel***; James E. Arzouman for ***Susan M. Arzouman***; Rene Mouledoux for ***Cathleen Mouledoux***; Grace Ann Feczko for ***Robert Zieles***; the many friends and husband of long time member, ***Dorothy Shell***, Dorothy helped a host of people with her book and her love.

In Honor

The American Porphyria Foundation is working to improve the health of those who suffer with this rare disease through outstanding physician and patient educational programs. We thank those people who honored their loved ones with a donation to the APF.

Allene C. Martin, Jolynn and Keith Foldesi, Mary Frances Donnelly, Paula and Robert Hendrix, Gary E. Eyster, William Kent Martin, Ruth Wilson, Nicole Diaz, Eric S. Gray, Lori Hanson, Grayfred Gray, Lawrence Pritchard for ***Ralph Gray***; Richard J. Drew for ***Michael J. Drew***; Lauren Miralia for ***Peggy Friberg Miralia***; William R. Whittenburg for ***Jocelyn and Jamie Whittenburg***; Mira and Paul Geffner for ***Edward Geffner and Desiree Lyon Howe***; Robert Quigley for ***Dr. Peter V Tishler***; Mr. Michael A. Pagano for ***Andrea Pagano Reyes***.

National Rare Disease Day: February 28, 2011

Each year Rare Disease Day has enjoyed an ever growing number of participating countries and more than a thousand patient organizations organizing events from tree planting to round tables, from marathons to art exhibitions. It has furthered rare disease as a public health priority, has shed light on the need for closer collaboration between patients and researchers, and now continues to underscore the challenges rare disease patients and their caregivers face. People Living with Rare Diseases should be entitled to the same access and quality of care as any other patients. But today the reality is far from that. The rarity of patients, medical experts, knowledge and resources are aggravating the vulnerability of rare disease patients who are suffering from life threatening, debilitating, and chronic diseases. We are certainly not asking for more or better access and care than for other chronic diseases. To the contrary, we share the common cause of all chronic diseases. However, we believe that rare diseases is one of the most dramatic cases of health inequalities today both internationally and in particular in Europe. Therefore, the APF participated in activities nationally and joined a host of other countries around the world promote Rare Disease Day. For example, Stephanie Simpko manned a Living with Rare Disease Day table at her local hospital.

Terri Witter has been a member of the APF for a long time. Her story reflects many of years. Her story, which follows, is similar to that of many of you.

When I had surgery when I was 21, I didn't improve. Instead, I spent the entire summer in pain, throwing up, no feeling in my hands and feet, and blisters on my arms. Although the doctors ran many tests, they could not come up with an answer. Finally, in desperation, our family doctor sent me to Mayo Clinic. After six more weeks of intensive tests, a doctor came in with a grave look and said, "You have Acute Intermittent Porphyria." He didn't look very happy, but I had the weight of the world lifted from my shoulders, because I finally had a name for what plagued me. That diagnosis was my present for my 22nd birthday. I had been given a barbiturate, which is an unsafe drug. I also had developed staph infection and been given sulfa, another unsafe drug, all of which had made me very ill.

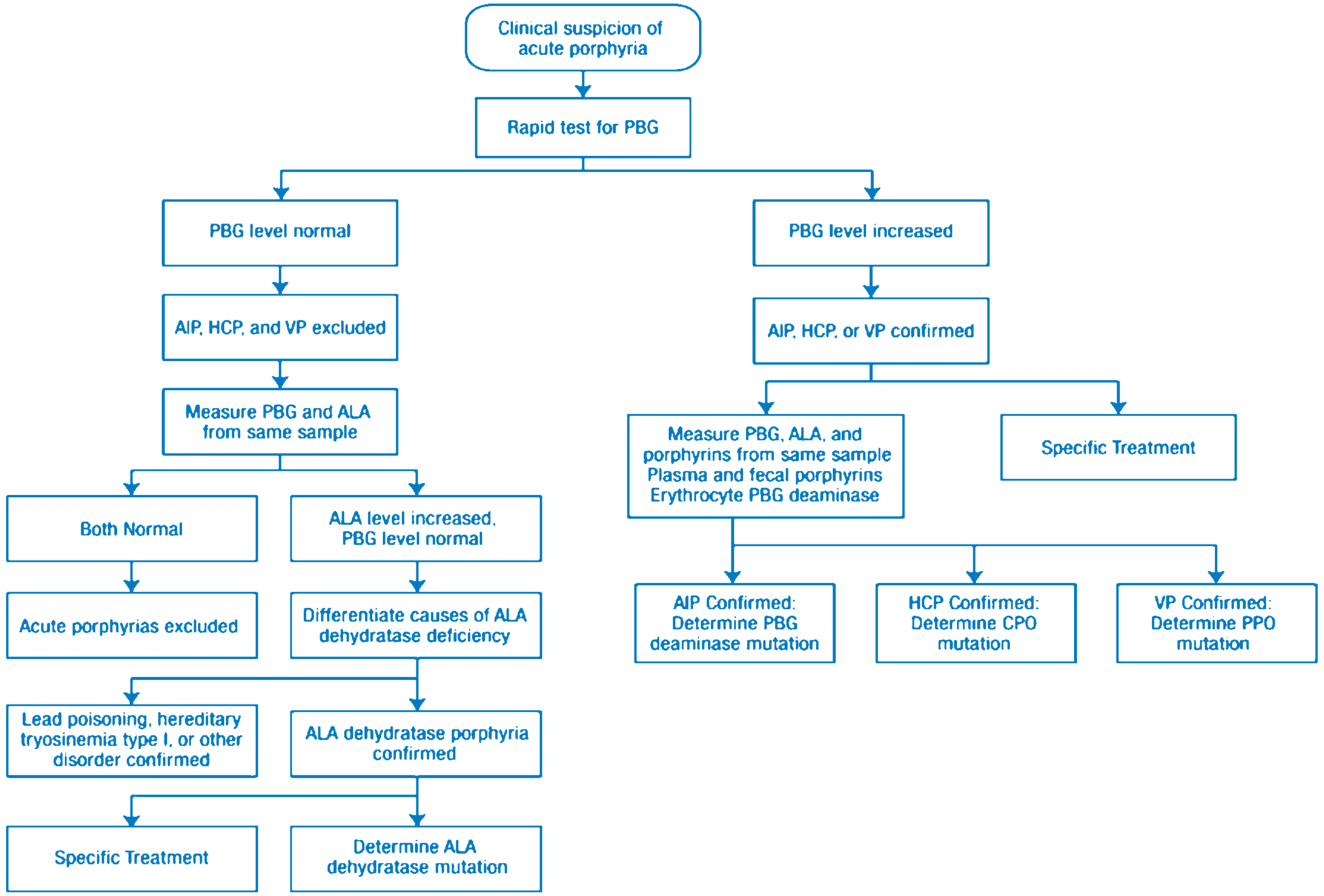
The doctor went on to say, "We have no cure. We don't know much about the disease. All we can do is try to keep you comfortable." That was 35 years ago. I have spent a lot of time in hospitals and nursing facilities, but through it all, I have learned a lot and met many interesting people. I have been a participant in five research projects so hopefully my struggles have helped someone. When I was first diagnosed I was so frightened. My mother and I spent hours in the college libraries reading about porphyria. The doctors here didn't know about porphyria either. I also wanted to find someone else with whom I could share my "misery". During a visit to expert, Dr. Claus Pierach, he told me about the APF newsletter and asked if I wanted to put my name on the mailing list. I am so glad I did. Terri went on to say the following:

> **"The American Porphyria Foundation has been my support group, my fountain of knowledge, my rock! They are the "Jerry Lewis" of Porphyria — raising money for research, supplying educational pamphlets and Emergency Room booklets, and a website for doctors and patients, organizing get-togethers to help us find each other. In short, a God Send and Answer to Prayer.**
> ***Thank you, Terri*"**

Testing Chart

Members have requested that we reproduce the following chart to help them understand the tests used to determine if an acute porphyria could be their diagnosis. Notice the importance of the PBG test. When acute porphyria is suspected, confirmation should be initiated immediately by biochemical or DNA testing. Measuring urinary PBG is most important for diagnosis of acute porphyrias. Porphobilinogen (PBG) excretion is normally 0-4 mg/day and is approximately in the same range when expressed as mg/g creatinine or even as mg/L. In an acute attack, spot urine (PBG) levels are substantially increased (20-200 mg/L).

The test should be established at the local hospital pathology clinical chemistry department. It is recommended that all medical centers provide for rapid testing for increased (PBG), since sending samples out to a referral laboratory can greatly delay diagnosis and treatment. Thereby, when acute porphyria is suspected the diagnosis can be ruled in or out in a timely fashion. The experts recommend rapid detection of increased urine por-phobilinogen (PBG) using the Rapid PBG tests, **Thermo Scientific Porphobilinogen (PBG) Kit TR520001** (www.thermo.com/diagnostics). The tests can be completed within 20 minutes. Your local laboratory can order the kit, by calling **1.800.528.0494 and press option 2**. Patients often ask if they can perform the test themselves and the answer is "NO". This test requires laboratory expertise.



Further diagnostic tests can only be sent to only a few specialized labs in the country. For example, the Porphyria Center at the University of Texas Medical Branch in Galveston Texas has a Porphyria Laboratory headed by Dr. Chul Lee. All biochemical tests for each of the porphyrias can be performed there. If you are having difficulty getting a diagnosis, please call the APF 1 866 APF 3635 or see the website for a list of laboratories.

Thank You **Mike Kensworthy and Matt Johnson who will be meeting with the FDA as representatives for EPP patients. They will share their life long experience, including their recent experience as participants in the clinical trials using Afamelanotide. The FDA Office of Orphan Product Development will be filming a video of Mike and Matt for the reviewers and other FDA representatives to help them better understand the great need for treatment. Watch for the fall APF newsletter for an expanded story on their visit to the FDA.**