



Merry Christmas and Happy Holidays

We Pray God's Blessings for a Happy and Healthy New Year.
Together we have made great strides in diagnosis and treatment of the porphyrias.
We look forward to even greater success in the coming year.
Yvette, Africa, Carol, Sarah, Mira, Lelia, Desiree



The American Porphyria Foundation is *your* foundation. We exist to better the health of porphyria patients by enhancing public awareness about porphyria, educating patients and physicians about porphyria, and supporting research to improve treatment and ultimately find a cure.

What is so special about the APF?

That's easy. We founded this organization with an active Scientific Advisory Board filled with doctors who have a history of doing porphyria research and the publications to back it up. Their knowledge forms the backbone of our educational materials, and their continued interest in and dedication to study of the porphyrias provides a strong guiding hand for the education and research aspects of our mission.

A National Institutes of Health official asked recently if we interact much with our board of experts, and we answered with a resounding, "YES! Almost every day." Apparently this level of involvement is unusual among rare disease organizations, and this knowledge makes us that much more grateful for the generosity these physicians have shown us.

As all of us do, our advisory board has aged during the APF's 27-year history, and some day its members will all have retired. While we are saddened to be nearing the end of our working relationship with a group of doctors who have become dear friends, we are heartened by one of their most important contributions yet: the time and energy they are giving to training a new generation of porphyria experts.

We thank our Advisory Board members for another year of dedication to our mission: the APF could never have existed without you. And we thank the new generation of doctors as well: our hope for the future rests with you.

What does the APF offer our members?

- A library and website full of expert-authored medical information, written for a lay audience.
- A dynamic collection of continuing education resources for physicians, online and in print.
- A referral service connecting treating doctors with porphyria experts for consultation.
- A searchable database of medications that are safe or unsafe for use in the acute porphyrias.
- A member support and information-sharing network with meetings throughout the United States.
- A host of materials to help you become a porphyria educator in your own community: *Porphyria Live* (DVD), slide shows and more!
- Links to additional support resources through our relationships with other health organizations.
- This quarterly newsletter, including up-to-date information on new clinical research, member stories, and other health and porphyria news.



Yvette, Africa and Desiree

This is a team effort. The APF includes our staff and Board of Trustees, our Scientific Advisory Board, and you, our members. We rely on your volunteer efforts and on your financial support to sustain all the work we do. With all of our active participation we will conquer porphyria. If you'd like to help but are unsure of how you can, just let us know and we'll point you in the right direction.

So You Have Acute Porphyria, What Do You Do Now?

Patients newly diagnosed with acute porphyria have a lot to think about. For many, there's relief at finally having a diagnosis for these attacks of crippling pain and all the rest — at last, it's really not all in my head! For some there are questions: where did this come from? If it's genetic, why didn't I know about it before, why am I the first one in my family to be diagnosed? What happens now?



Most people who inherit a gene for acute porphyria will never become sick with the disease. Among those who do have an attack, the majority will recover and live a perfectly normal life, never to be sick again. But some people who have a genetic mutation for acute porphyria will have repeated attacks throughout their lives, making the disease a regular fact of life.

For all people with acute porphyria — even those who never become sick — prevention is crucial. Doctors don't yet know why some people in a family will get sick and some won't, or why some will have only one attack in a lifetime while others will have 100. So for everyone at risk for an acute porphyria attack — everyone who has the gene for the disease — avoiding the triggers for an attack and taking a couple of other simple precautions are essential parts of ensuring the best possible longterm health. Luckily, the APF has something that can help: the **Primary Care Physician & Emergency Room Kit**.

The kit is a binder with your name on it. It contains everything your regular doctor needs to keep you healthy and will help your emergency room doctor manage you in a crisis:

- **Annals of Internal Medicine** article by seven porphyria experts on diagnosing and treating acute porphyria;
- A **step-by-step guide** to diagnosing porphyria;
- **APF pamphlets** on managing acute porphyria and Panhematin treatment;
- Instructions for collecting lab samples and a **list of laboratories in the U.S.** your doctors can rely on for accurate testing and interpretation of the results;
- Instructions for preparing **Panhematin** for infusion;
- Information on **rapid PBG testing kit** (for use in laboratories only); and
- A **list of safe/unsafe drugs** for use in the acute porphyrias.

The kit also has a place for your personal medical records — the results of lab tests diagnosing you with porphyria. APF member and acute porphyria sufferer Terri Witter says the kit is fantastic and that "everyone should carry something like this." Terri has added an updated list of the medications she is currently taking to the kit and has used the materials in it to educate the nurses who treat her about the fact that an acute porphyria attack "can make you feel really awful." She reports that her doctor has also become much more comfortable treating her porphyria since learning from the materials in the kit and getting familiar with the APF website.

You can buy the **ER/Primary Care Physician Kit** from the APF for \$35. Those with EPP, please call the office for more information about the **EPP Working Kit**, which contains similarly useful information for managing EPP.

Porphyria Awareness Week 2009

Porphyria Awareness Week is **March 28 - April 4, 2009**. What will you do to mark the season? Last year our members organized *In Touch* meetings; brought attention to porphyria on national television, on the radio and in newspapers; and hosted educational events at local and regional hospitals.

We've got one *In Touch* meeting on the Porphyria Awareness, 2009 calendar already, and **the APF can help** you realize whatever ambitions you have for the week, or offer you suggestions if you need an idea. So call us up and **let's get planning!**

FDA Consumer Complaint System

Do you have a complaint about a product regulated by the Food and Drug Administration (FDA)? The FDA wants to know about it and you can report it through the Consumer Complaint Reporting system or MedWatch. Read all about it at: www.fda.gov/consumer/updates/reporting061008.html

Do You Have PCT? Don't Forget the Updated Brochure!

Thanks to a generous grant from member Dolores Brazas and the hard work of Dr. Maureen Poh-Fitzpatrick, the APF recently printed an updated version of our brochure on diagnosis and treatment of Porphyria Cutanea Tarda (PCT).

If you have PCT and have not yet ordered your copy, don't forget to call the office and do so!



Francis Collins Steps Down — Major Figure in Human Genome Race



Francis Collins stepped down in August from his directorship at the National Human Genome Research Institute, at which he worked for years to sequence the human genome and make the results of his research available to scientists everywhere.

Dr. Collins has made huge contributions both to medical science and to the ethics of practicing that science. After successfully sequencing the genome (laying out, in order, all the genes that make up a human's DNA), Dr. Collins began to spend time addressing the ethical implications of humans having this knowledge. Now that we know, in rough terms, what the genetic code that makes people go looks like, what do we do with that information and what should we do with it?

In some ways, Dr. Collins became famous for coming in second in the race to decode the genome, a contest of such importance to science that a play (*The Sequence*) dramatizing it is now in performances in Pasadena, CA. First to decode the genome was Dr. Craig Venter, in a privately funded effort. But Dr. Collins kept working, and the results of his research are freely available for doctors and scientists to use in their research.

As advocates for people suffering with genetic diseases and beneficiaries of Dr. Collins's work, the APF takes this time to say Thank You. We know that the search for our cure would not be where it is today without your work, and we are deeply grateful.

The Mount Sinai Porphyria Center: Working for Your Good Health

The Porphyria Center of The Mount Sinai Medical Center in New York offers consultations, clinical evaluations, and genetic testing for the porphyrias. The Porphyria Center Team will review records and provide consultation on possible diagnoses of porphyria. Patients with confirmed diagnoses of porphyria (by biochemical and/or DNA testing) can schedule appointments for clinical evaluation and consultation with Dr. Manisha Balwani and Dr. Lawrence Liu at The Porphyria Center. For an appointment, please call: 212-659-6779.

Patients having their records reviewed at the Porphyria Center can expect to send biochemical (urine, blood or stool) test results related to porphyria diagnosis. If you don't have all the test results they need to evaluate your condition, you will need to provide blood, urine and/or stool samples for testing. You will receive results in about three weeks. Often it takes time and a collaborative effort to correctly interpret porphyria test results.

Because porphyria is so rare, Porphyria Centers, such as the one at Mount Sinai and the University of Texas, are available to help you and your primary care physician with diagnostic testing and interpretation of the results. All of us understand how frustrating it is to not have a diagnosis or to be concerned about the reliability of the diagnosis. Doctors at the porphyria specialty centers will do everything they can to determine your diagnosis. For some patients, this could mean repeating your previous porphyria tests for urine, blood or stool.

The Mount Sinai Porphyria Center also offers DNA testing for seven porphyrias: AIP, HCP, VP, f-PCT, HEP, EPP and CEP. Before requesting DNA testing, it is recommended (though not required) that patients have biochemical testing (urinary, stool and/or plasma porphyrins and porphyrin precursors [ALA and PBG] and/or enzyme assays). DNA testing is costly and, unlike biochemical testing, is not usually handled by insurance.

Biochemical testing may confirm that a person has porphyria and help determine what type of porphyria it is. DNA testing typically takes 2-4 weeks.

UTMB-Galveston Porphyria Center has been a major international center for treatment and diagnosis for over two decades. They offer consultations, clinical evaluations, and biochemical testing for each of the porphyrias, as well as clinical research. The UTMB Porphyria Center is back up and running after Hurricane Ike and is recruiting PCT patients for a study. *If you have PCT and are interested in volunteering for a medical study, please call the APF office for more information.*

Clinicians Dr. Karl Anderson and Dr. Gagan Sood, together with laboratory investigators Dr. Chul Lee, Dr. Csilla Hallberg, Dr. Jeffery Wickliffe and Dr. Sherif Abdel-Rahman, provide research, laboratory diagnosis and medical assistance for patients around the world. Much of the training for the *Protect the Future* program also takes place at the Porphyria Center in Galveston.

Individuals in need of diagnosis or treatment can schedule an appointment at the Porphyria Center or have their samples sent to the laboratory for testing and interpretation by one of the clinicians.

For more information about the Mount Sinai or UTMB clinics or to find out about scheduling an appointment with a porphyria expert in San Francisco, CA, Charlotte, NC, Louisville, KY, Boston, MA, St. Louis, MO, Salt Lake City, UT, or at the porphyria clinic closest to you, please contact the APF.

Renew Your Membership at our website: www.porphyrifoundation.com,
or call us at the office: 1.713.266.9617 or 1.866.APF.3635.
Thanks!

APF Educates Doctors — You Can Too!

As we've done for many years now, the APF staffed a booth for three days each at the American Association for the Study of Liver Diseases and American Society of Hematology medical conferences this year. Both meetings were held in San Francisco.

APF members Monica Firchow and Molly Buffington volunteered to join staff member Mira Geffner at the APF table, where we spoke with doctors who had questions about managing or diagnosing patients with porphyria. All three of us at the table



Molly helped out after dealing with AIP for years.

are affected by porphyria, Molly and Mira by the relatively commonplace Acute Intermittent Porphyria (AIP). Monica's father, Gene Bennett, lived a long and interesting life despite a lifelong battle with the rarest of the porphyrias: Congenital Erythropoietic Porphyria (CEP).

From the APF's inception, educating doctors about the porphyrias has been a central part of our mission. This priority was born in part of APF founder Desiree Lyon's

difficulties learning that she had porphyria, and the years of suffering that preceded her diagnosis. An intimate understanding of the embarrassment and frustration that patients go through when their doctors do not know to look for porphyria or do not know how to make the diagnosis is at the heart of the work we do.

No special expertise is required for patient volunteers looking to educate their doctors or others. To staff a booth or a table, being familiar with the literature you have on hand is enough. If you want to put on an informational session for nurses at your local hospital as some APF members have done, you'll need to study the materials a bit beforehand.

The APF staff can guide you through the medical information we have available, all of which has been written or approved by our Scientific Advisory Board — men and women who have been studying and treating the porphyrias for decades. These materials form the backbone of our educational work, allowing us to relay medically accurate information to doctors and patients for accurate diagnosis and better care.



Monica's daughter came along to the Liver Meeting.

In Memory

We are saddened to hear of the passing of our dear friends. Some of their loved ones have chosen to honor a life by making a gift to the APF. We sincerely appreciate their thoughtfulness and desire to help others with the disease. Please join us in thanking:

Helen L. Chanowsky, Mary G. Carleton, Catherine M. Henderson, Maggie Leitstein for *Alice "Patsy" Brady*

Sharon and Gerald Hiles, Danny L. Hiles, Marca Hispanic, LLC for *Ian Maynard*

Carole and Glenn Kuklewski for *Vince Kuklewski*

Susan L. Engel, MD for *Lee Engel*

Denise M. Halbach, Leslie Dellinger, Katherine B. Ellis, Sara and David Thompson, City of Winston-Salem Fire Department (on behalf of Fire Engineer and APF Member Jonathan Pike), Shirley I. Robertson, Deborah and Steven Sorrell, Deborah R. Loggins, Philip G. Hill, Richard and Robin Miller, The Knolls Men's Golf Association, Wyatt Vanoy and Nancy I. Idol for *Marcia Pike*

David H. Panzera, Nancy J. McCormack, Tina and Doug Jenne and KarenLu LaPolice for *John H. Giacobbe*

Ruth M. Murtha, Stephanie D. Sizemore, Ruth L. Smith, Doris J. Stanley for *Raymond Smith*

Kathleen Toelkes for *Donna Pagano*

Michelle Letkemann for *Walter Cernik*

In Honor

Others have chosen to honor their friends through a gift to the APF:

Alicia A. McCord for *Monica Firchow*

Zila Reichman for *Dorit Reichman Ovardia*

Mary Ann M. Kopic for *James, Kathleen and Robert McGucken*

Marc E. Robinson for *Andy Turell*

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

Houston Gets In Touch



In mid-October, while parts of the city were still putting themselves back together after Hurricane Ike, long-time APF member and EPP patient Ann Warnke hosted an **APF In Touch** meeting at her home in Houston. (Ann's story was in the last issue of the newsletter, and you

can find it on our website.) Dr. Claus Pierach, noted porphyria expert and APF board member and all-around kind and compassionate human being, joined the meeting by telephone as the featured speaker.

Dr. Pierach spoke for more than an hour about the porphyrias, which he describes as a labor of love as well as a career for many years. That is why he continues to serve on the APF Scientific Advisory Board and speak at member meetings several years into his retirement from medicine. Dr. Pierach was one of the scientists who did early research on the drug that we now know as Panhematin, so alongside others, we have Dr. Pierach to thank for giving us a treatment for acute porphyria more advanced than simple sugar.

A couple of meeting highlights:

- Always remember the importance of both a high carbohydrate diet and avoiding fasting, especially for people who have acute porphyria. Even acute porphyria patients who are very careful about their diets can get into trouble with fasting when a scheduled medical procedure means skipping or delaying breakfast. If a surgery gets behind schedule, that can mean extending a fast from overnight to nearly 24 hours. That's no big deal for a healthy person, but is potentially dangerous for a porphyria patient, especially once you factor in the physical stress of surgery. Dr. Pierach reminds patients to fast for as short a time as possible (scheduling surgery for the morning is a good idea), and recommends that if a procedure is postponed at all, patients should insist on having a glucose IV so that they will have a source of calories and carbohydrates.
- One man came to the meeting for more information about diagnosing acute porphyria because his niece is very ill in Argentina. The APF website includes information on Panhematin in Spanish, and we have a global partners program with links to porphyria centers and organizations around the world to answer this need as well. Just as porphyria researchers meet internationally to pool scientific data, we want to join our efforts with those of other patient groups internationally to all of our benefit.

Southern California Support Group

The long-standing Southern California porphyria support group got together at the end of September to share stories and ideas about dealing with persistent symptoms of acute porphyria. People at the meeting were dealing with the acute porphyrias, with some still seeking definitive diagnosis. Cherry and Thom Schillinger hosted the meeting at their home outside Los Angeles.

The APF provided informational pamphlets and Mira Geffner spoke briefly to the meeting to give an overview of the porphyrias and of what we offer our members. Conversation hit on the importance of making one's doctors aware of the safe/unsafe drug database for the acute porphyrias (<http://apfdatabase.com/>), following a healthy diet high in carbohydrates, and staying indoors — an especially important point for photosensitive people living in sunny Southern California!



It's always good to see this group getting back together, since the chance to meet another porphyria patient face-to-face is a big deal for a lot of people dealing with the diagnosis. Meeting and talking with others can be an important source of support and hope.

Check your ENews...

More meetings coming up in the next six months

We get calls at the office every day from members who want to know when the next meeting in their area will be. The best way to get to a local porphyria meeting is to host one yourself.

The APF will invite members in your area, collect RSVPs and arrange for a speaker if you'd like to have one. You can host a one-time meeting, or aim to start a regular group — whatever you need, we're here to help!

Rolling Meadows, IL — April 4, 2009

(Hosted by Dee Bruno)

Olympia, WA — Date TBD

(Hosted by Esther Bandy)

Lebanon, OH — May 2009

(Hosted by Steve Stevens)

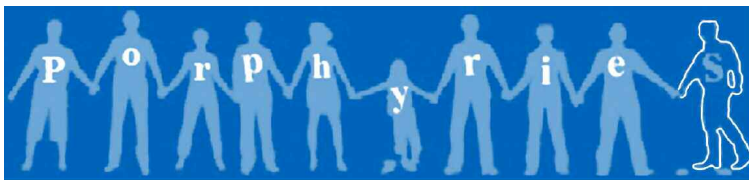
Fort Collins, CO — Spring 2009

(Hosted by Rene McLellan)

Don't see a meeting near you? Call the APF office to see about adding an **APF In Touch** meeting in your area.

1.866.APF.3635 or **1.713.266.9617**

New Friends in France



We are delighted to welcome a new overseas porphyria group, the *Association Française des Malades Atteints de Porphyries* (French Association of Porphyria Patients), to the community of porphyria educators and advocates worldwide. The group is planning to mark its foundation at the beginning of the New Year, with a kick-off meeting in Paris, where patients and their allies will have a chance to get together and inform themselves about porphyria.

Association President Sylvie Le Moal writes: "Our association aims at helping patients to better live with their diseases, to create a friendly community while organizing fund raising to find new resources to aid research. Of course, we work hand in hand with the *Centre Français des Porphyries* (the French national porphyria center) and Pr. Jean-Charles Deybach and his team."

The Association's further goals are very similar to those of the APF: to increase awareness of the porphyrias and their treatment in the general public and within the medical community, and to serve as an envoy and advocate for the needs of porphyria patients as necessary.

The Association's website is up and running at <http://www.porphyrries-patients.org/> though it currently exists only in French.

Congratulations to our new French friends! We're very pleased to see that people affected by porphyria in France and in the French-speaking world will have a new resource, and we look forward to working with you — combining our efforts towards ever-better health and eventually a cure.

Remember the APF for the Holidays

*Porphyria is an extremely painful illness and can be life-threatening. The **American Porphyria Foundation** is working to improve the health of those who suffer with this rare disease by disseminating accurate medical information to patients, educating physicians in appropriate diagnostics and care for the porphyrias, and supporting advanced training for a new generation of porphyria experts.*

The holidays are a wonderful time to help us advance our mission. Your tax-deductible donation by check or credit card will help us continue our educational work and foster research efforts and the search for a cure.

Thank you.



Rare Disease Grant Moves Forward

It is our pleasure to inform you that with your generous support, we have successfully completed the campaign to raise \$100,000, qualifying us for a \$500,000 challenge grant from an anonymous donor. This combined \$600,000 is strong testimony to the porphyria patient community's support for research that will improve our health. As you know, the active participation of a patient organization is one of the criteria the National Institutes of Health (NIH) will consider when it decides whether or not to give \$5 million for porphyria research.

We could never have come this far without you, and we thank you.

Lots of Work Still Ahead

While we wait for the NIH decision, the APF is charging forward and again we ask for your help. If you have not been in touch with us in a while, please make sure we have all of your current contact information — Full Name, Address, Phone Number and Email Address. You can do this through our website, via email or by calling the office.

We are collecting your contact information for a national porphyria patient registry. This will eventually be a record of all porphyria patients in the U.S. Researchers will finally be able to develop a good idea how many of us there are, how many have each type of porphyria, and what proportion of people who have a genetic mutation for porphyria will become sick with the disease. Personal information contained in the registry will of course be completely private, and any discussion of individual patients will remain anonymous.

The registry information is vital to diagnosis (doctors around the U.S. will have a true picture of porphyria's prevalence and be able to consider the diagnosis accordingly), to fundraising and lobbying (we will be able to approach private and government sources with substantial evidence of our numbers and our needs), and of course to research (the registry will provide a pool of potential research volunteers, as well as a census of people whose treatment choices and condition can be tracked and analyzed over the long term).

You can still help us build the registry

Please let your family members or friends who have porphyria know about this effort and encourage them to get in touch with the APF. While we would love to have you all as members of the foundation, the registry is a universal goal and is not tied to membership. So please, give us a call. With your help we can work harder for your health.

Come Cook With Us!

Do you have a recipe to share? Maybe one that's wrapped up in family lore? The APF wants your recipes, inspirational stories and tips for a commemorative book to be published in the coming year. So go ahead and send them in, or give us a call to learn more!





Genetic Discrimination — It's Against the Law

For many people who have a relative with porphyria, the thought of genetic testing is too scary to consider. What if you have the disease? Will it affect your future? Your employment? Your health care?

After 13 years, the Federal Genetic Information Nondiscrimination Act of 2008 (GINA) has been signed into law. The law's health insurance component — barring insurers from denying health insurance to individuals with a genetic predisposition toward disease — will go into effect in May, 2009. The part of the law intended to prevent employers from discriminating on the basis of genetic status will become effective in November, 2009.

Genetic discrimination is an issue as doctors and scientists learn more and more about the mutations (changes) in our genes that could cause us to become sick or make it more likely that we will develop a certain illness. There has been concern that if a 20-year-old woman finds out she is more likely to develop breast cancer, for example, employers could turn her down in hiring decisions or insurers could refuse her health coverage. The object of GINA is to protect people from being denied access to jobs or insurance for a disease they may or may not ever develop.

The concerns addressed by GINA have been an issue for porphyria families — especially now that genetic testing is available for seven different types of porphyria in the U.S. Once one family member has a confirmed porphyria diagnosis, she or he can have a DNA test to find the mutation for the family and other family members can learn whether or not they have a gene for porphyria. Under GINA, family members who have the genetic mutation for porphyria but have never shown symptoms should be as free to find employment or health insurance as anyone else.

GINA does not change anything for those who have already been sick with porphyria. The law is not intended to affect people who suffer from a genetic disease, but to simplify the decision to find out about your risk of developing a given condition.

More FDA Funding for 2009

The APF was one of the original members of The Alliance for a Stronger FDA, whose focus was to encourage Congressional action to assure increased funding for the Food and Drug Administration (FDA) in fiscal 2009. The APF and other consumer groups have called for strengthening FDA by increasing its federal appropriation. Now, both houses of Congress have passed a Congressional Resolution to do just that.

Turned Down for Disability? SSA Wants to Help

The Social Security Administration (SSA), the branch of government that makes decisions on individual disability benefits, is looking for input from doctors and patients on rare diseases. Last December the SSA started looking to learn what barriers face patients with rare diseases who are seeking disability benefits. The APF wants to help porphyria patients seeking disability benefits now and in the future by gathering your stories about your experiences — both positive and negative — with the SSA.



As many porphyria patients who have filed for disability know, part of the difficulty of obtaining benefits is educating case reviewers about what porphyria is, and helping them to understand why this could be a disabling disease. Rather than simply describing your own condition and obtaining your doctor's testament to that condition, you may have found yourself in the position of trying to demonstrate the medical reasons that porphyria can cause the level of disability that it too often does.

The SSA has an approved list of diseases for which applicants may be granted benefits, and naturally many rare diseases are not on this list. Having a disease appear on this list does not mean that everyone who has it will automatically be awarded disability benefits, but it will at least increase the reviewers' familiarity with the condition. All people applying for benefits are required to demonstrate that they are unable to work because of their medical condition.

The APF would like to hear from you: both patients and doctors. Have you been turned down for disability due to porphyria? What supporting documentation did you provide? Did you try the appeals process? Did you find that it answered your concerns and your doctor's? How did you find the reviewer's reaction to porphyria as a rare disease?

If you'd like to share your story, please get in touch with us at the APF office and let us know.

The SSA wants to hear from doctors too, so please let your doctors know about this as well. The questions for doctors are:

1. Are there any generally accepted functional scores or scales of progression that medical professionals rely upon in determining functional impairment?
2. Are there any generally accepted clinical tests (including genetic or other bio-markers) which can be relied upon to diagnose a disorder or to determine a patient's stage of disease or level of functional impairment?
3. Given the natural history of the disorder generally, is there a certain age (or time since onset) at which the person's functional impairments typically become severe?



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

National Porphyria Patient Registry: The APF is still building a registry of porphyria patients in the United States. You can help by asking family members who have porphyria to contact us. See page 6 inside for more details.

The **Drug Safety Database For The Acute Porphyrias** is available at <http://www.apfdrugdatabase.com/> We will include a calling card with this information in all new member packets, in the ER kits and for those who send a stamped, addressed envelope.

Is Your Membership Up to Date? We rely on our members to help us keep the drug database and other services going. Please take a moment to renew at our website, or call us at the office: 1.713.266.9617 or 1.866.APF.3635. Thanks!

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