

Thank You, Dr. Bottomley!



The APF is proud to announce publication of Dr. Sylvia Bottomley's newly revised chapter, "The Porphyrrias," in *Wintrobe's Clinical Hematology* (12th Ed., 2008). This is the sixth edition of the chapter on porphyria Dr. Bottomley has written or revised, and it is an authoritative overview of the porphyrias.

Dr. Bottomley has been a member of the APF Scientific Advisory Board since our founding

in 1982, and, in addition to her textbook publications, has cared for patients with various types of porphyria at her clinic. She has also been both a consultant and lab specialist in the care of many others. As so many porphyria specialists already have or soon will, Dr. Bottomley has retired from clinical practice, but she retains her interest in the porphyrias and continues to contribute to education on these very rare diseases.

Dr. Bottomley writes: "I got into the porphyria field early on and by default when I embarked on the heme field in the red blood cell system. After I learned porphyrins and porphyrias in Dr. C.J. Watson's* place in 1963, I also performed all porphyria tests needed for patients in our area in my research lab, until grant monies no longer allowed it and the Watson lab made it available (for a fee). This all seems like so long ago, and I would do it again."

Dr. Bottomley's career has included some major highlights in porphyria research. Her lab first reported the enzyme defect in EPP in 1975; she did an early patient study (in the 1980s) on the association of PCT with inherited hemochromatosis (an iron overload disorder); and helped to develop scientific understanding of the PBG-D enzyme.

Although Dr. Bottomley has retired, she continues her long-standing research on sideroblastic anemias (like porphyria, these are disorders of the heme pathway), and continues to advise the APF on its work as a member of our advisory board.

On a personal note, I had the pleasure of meeting Dr. Bottomley at the American Society of Hematology (ASH) meeting last December, when she came to visit us at the APF exhibit booth. As both a scientist and a physician, she has clearly been a passionate advocate for porphyria patients throughout her career. We can all be grateful for the contributions that Dr. Bottomley has made to our care and well-being.

Dr. Bottomley in turn spoke about the satisfaction of having studied the porphyrias over a half-century long career in medicine — from a time when relatively little was understood about the biochemistry of the diseases, up through today when doctors have identified the site of the genetic defect (mutation) for each of the eight types of porphyria.

Visiting our booth at ASH also gave Dr. Bottomley a chance to

meet Monica Firchow, who is writing a book about her father, Gene Bennett, who suffered from the very rare Congenital Erythropoietic Porphyria (CEP). As so many doctors who study the porphyrias have, Dr. Bottomley had seen photographs of Mr. Bennett's face and hands. Indeed some of his photos appear in her textbook chapter to illustrate the effects of the sun in CEP. But she had no personal connection to the patient in the pictures. Monica and Amy Love (another member from San Francisco) both greatly enjoyed meeting Dr. Bottomley as well.

*Dr. C.J. Watson was one of the scientists behind the Watson-Schwartz test, an early screening test for diagnosis of acute porphyria. If this test shows excess porphobilinogen (PBG) in urine, doctors order a more precise test to quantify PBG and determine if the patient has an acute porphyria.

— Mira Geffner

Porphyria Education for MDs

The APF promotes comprehensive health care necessary to manage life with porphyria. We encourage members to call the office and request a free **Acute Porphyria Physician Education Kit** for your doctor. Treating physicians can also get information about consulting a Porphyria specialist on diagnosis and patient care.

Acute Porphyria Physician Education Kit contents:

- "Diagnosis and Management of the Acute Porphyrrias," (*Annals Int Med*, March 2005);
- **APF Brochures** on all of the porphyrias (written by porphyria experts);
- Detailed information on **biochemical and genetic testing** for porphyria;
- Detailed information on **treatment of acute porphyria with Panhematin®** (hemin for injection), and preparing hemin with albumin.

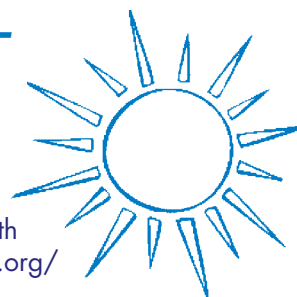
The APF also offers:

- An acute porphyria **Drug Safety Database**;
- Two **Continuing Medical Education** courses on Porphyria (online, free of charge to practicing physicians);
- A **PowerPoint presentation**, suitable for detailed presentation to students and hospital staff;
- **Porphyria Live** (30-minute educational DVD focusing on PCT, AIP and EPP, features patient stories and extended specialist interviews).

For more information, call 713-266-9617 or 866-APF-3635.

Summer Is Coming —

EPP & CEP families might want to prepare for summer by looking into Camp Sundown (for photosensitive children) www.xps.org/campsundown.htm or Camp Discovery (for children with skin diseases) www.campdiscovery.org/



Experts-in-training to Join International Porphyrin Conference

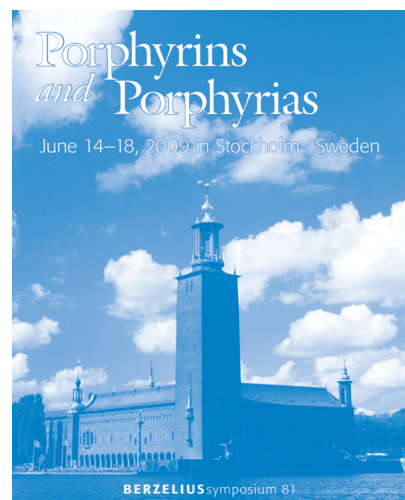
The **International Conference on Porphyrins and Porphyrins** will take place in Stockholm, Sweden, June 14-18. The meeting will be held this year in the Swedish Society of Medicine Building, and includes a reception at the Stockholm City Hall, where Nobel Prize festivities take place every year. This year, we are proud to announce that doctors in the APF **Protect the Future** program will attend the conference and have the opportunity to meet Porphyrin experts from all over the world in the beautiful city of Stockholm.

Attendees meet every two years at this prestigious conference to discuss the latest developments in Porphyrin and other heme-related disorders. Because these disorders are rare, opportunities for basic scientists, molecular biologists, laboratory and clinical academics, clinical researchers and physicians working in the field to come together and learn from one another are invaluable.

Sharing clinical and research experience is central to advancing and improving the scientific and medical approach to the disease. This collaborative scientific process is the basis for all of our current treatments and future advances. That is why the APF is spon-

soring the conference attendance of those of our experts-in-training who are able to go.

Protect the Future participants already see patients, participate in research and work together with the established experts on the APF Scientific Advisory Board. Your donations have made this additional educational opportunity possible, and will lay the foundation for ongoing international collaboration. Meeting with and learning from colleagues and mentors in an intensive setting will advance these young doctors toward their goal of becoming the next generation of porphyria experts in the United States.



New EPP Drug to Begin U.S. Trials



A new drug that could prevent or reduce sun sensitivity in EPP patients has received Investigational New Drug (IND) status from the FDA. This means that Clinuvel, the Australian company that makes Afamelanotide, can now begin clinical trials of the

drug here in the United States. Afamelanotide (formerly CUV1647) is already undergoing advanced clinical trials in Europe, and the company has tentatively reported positive results for EPP patients' sun tolerance.

Afamelanotide is being given as a tiny implant injected under the skin. It is designed to dissolve, releasing a controlled dose of the drug, over 60 days. It works by stimulating production of melanin in the skin to protect against UV radiation. The hope is that this will protect against EPP photosensitivity.

Afamelanotide received Orphan Drug Designation (ODD) from the FDA last July, an important regulatory step for all porphyria treatments. An "orphan" drug is one developed for a rare disease — any condition that affects fewer than 200,000 people in the United States. This pharmaceutical status was born of the Orphan Drug Act (1983), which gives incentives for drug makers to develop and market treatments for underserved patient groups. This is hugely important for treatment of rare diseases that affect far too few patients to make the usual drug marketing strategies profitable.

Please contact the APF if you are interested in information on volunteering for trials of Afamelanotide: 866-APF-3635.

In Memoriam, Dr. Derek Cripps

We extend our condolences to the family and friends of Dr. Derek Cripps, who studied the Turkish porphyria outbreak of the 1950s. Dr. Cripps died in January; he was 80 years old.

Dr. Cripps, a Dermatologist at the University of Wisconsin-Madison, studied photosensitivity throughout his career and developed the sun protection factor (SPF) rating system for sunscreens. Dr. Cripps also traveled to Turkey with other researchers on an Environmental Protection Agency grant to study porphyria there.



The Turkish porphyria outbreak is an interesting and alarming piece of porphyria history. Beginning in 1954, a food shortage forced people in southeastern Turkey to eat wheat seed grain that, in preparation for planting, had been treated with the fungicide hexachlorobenzene (HCB). More than 3,000 people in the region developed porphyria, and many breast-feeding babies under the age of one died.

Dr. Cripps and his colleagues went to Turkey in 1979 to investigate any lasting health effects on people who had eaten HCB-treated grain. They found that 20 years after having eaten HCB-treated food, patients were still suffering from porphyria symptoms, and that HCB levels in human milk were as high as 140 times what is allowed in cow's milk.

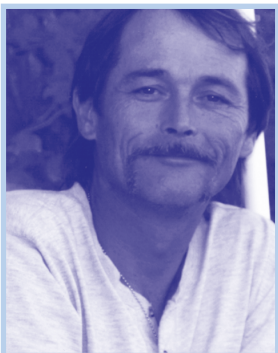
Being In Touch Helped Me

I want to share my experience with the In Touch network provided to us by the Foundation. I was diagnosed with AIP after 18 months of symptoms. You all know the severe abdominal and back pains with fatigue and nausea, but the scariest part was the rarity of this disease. Every doctor was unfamiliar with it, and very little was known about it. People look blankly when you try to explain how you feel, I don't have to elaborate to you all that also have it. So I decided to communicate with someone else who had this illness.

This was back in 2001, the time before the wonderful website that we are so blessed with now. So I opened the newsletter and looked at the names before me. I knew that I wanted someone that also had AIP. So I closed my eyes and asked God to help me chose the right one. I opened my eyes and there she was. Lori Brown, from Madison, Alabama. I am from Arkansas so she was geographically close to me. I emailed her and introduced myself, telling her all of my experiences so far and asking if she would like to share "war stories." She emailed back and was more than happy to do just that. So over the next seven years, Lori and I battled porphyria together.

After a while, Lori and I began calling each other on the telephone. Some of our conversations lasted for two hours! We discussed how the disease affected our marriages, children and our lives in general. I don't know if it was misery loves company but I can tell you she helped me so much. To have someone who understands what you are going through is great. I didn't feel alone.

On October 16, 2008, Lori Brown from Madison, Alabama passed away. Her battle with porphyria is over. She is free. I never got to see her face or give her a hug, but she was one of my best friends. So if you are thinking about getting in touch with someone and just haven't done it yet, I encourage you to find yourself a Lori too. Find several. I have others as well: Rose, Mira, Judy, Jennifer and Troy. Or attend a meeting near you. Or reach out and host one yourself. I can assure you it will be a fulfilling experience. — **Karen Eubanks** (Conway, AR)



Richard Dugger: My Diagnosis Took a Lifetime

Richard Dugger remembers having abdominal pain since childhood. But the pain worsened until "it was like a red hot spear poking all the way through my body from front to back. I felt like I was crawling out of my own skin and was fuzzy in the head. Sometimes I couldn't see clearly. My sister had all the same symptoms but we never thought that we had the same disease or that it could be genetic." Years of pain and sickness went by without a diagnosis.

Richard began to get discouraged, particularly when members of his own family began to doubt his illness. But his wife held steadfast. She had seen him at his worst — screaming in pain. Richard had so many sick days at work that he could no longer keep a job. He opened his own contracting business and worked as much as possible, but it was very difficult.

Richard's doctors removed his appendix and gallbladder, but neither surgery helped. When his urine looked like dark, bock beer, he was advised to take in more fluids.

Finally, Richard mentioned the intense abdominal pain to his rheumatologist, who said he had diagnosed a patient who had similar pain with acute porphyria, and he tested Richard for AIP. Two sets of tests came back positive, and since receiving treatment, Richard has started living a more normal life.

Richard felt both relieved and vindicated at having a diagnosis. His former doubters apologized. But Richard told them: "I even doubted myself at times."

In Memory

We are saddened by the passing of our dear friends. Some of their loved ones have chosen to remember a life with a gift to the APF. We are grateful for their desire to help others with the disease. Please join us in thanking:

Joe L. Yager for **Arlene Yager**, Dolores Brazas for **Wesley J. Brazas**, Diane L. Levere for **Dr. Richard D. Levere**, Ralph M. Gray for **Fred L. Gray**, Elaine Smuczynski for **Helen and James Smuczynski**, Vickie Gelm for **Judy Coley**, Brenda and Randall Wendland for **Debra Wendland**, Norma Brown for **Matthew Brown**, Yvette M. Strange for **Margaretha Morand**, Sophie and Edward Marshall for **Susan Marshall**, Beacon Converters, Inc. for **Richard Cantalupi**.

In Honor

We also thank the individuals who donated to the APF in honor of their families and friends.

Paula and Robert Hendrix, Mary Frances Donnelly, Randolph Wellford, JoLynn and Keith Foldesi, Sarah and Lawrence Pritchard, Kent Martin, Joseph Gray, Ruth Wilson, Gary E. Eyster, K.L. Hanson for **Ralph M. Gray**, Janet Brandon for **Lisa Kancsar**, Anne Wilson for **Pamela J. Flynn**, Kathleen E. Venter for **Patricia Wright**, Diane and George Pacquet for **Ken and Audrey Timper**, Connie Helleson for **Dorothy Shell**, David and Lara Quintero for **Suzette Cowles**, Christine L. Cowles for Suzette Cowles, Richard J. Drew for **Michael J. Drew**, Robert P. Quigley for **Dr. Peter Tishler**, Joanne H. Kitch for **Tracy Nadeau**.

*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.*

Steve Stevens: Diagnosed at 55



My Porphyria story starts in 1962 at my mother's funeral. She was only 32 when she passed away from neurological complications brought on by Acute Intermittent Porphyria (AIP). Both of her sisters and two of her three brothers had AIP.

The only test available for my mother was her urine turning dark when she was having an attack, and the only treatments she received were morphine or

Demerol for the pain. There was no Panhematin, and when she had an attack she would be admitted to the hospital for the duration, sometimes for as long as two weeks. All of my mother's siblings who had the disease passed away young. My own sister passed away from complications of porphyria in 2004, and one of her children has been diagnosed with it as well. Several cousins have been diagnosed with Porphyria or have symptoms.

I had no Porphyria symptoms for most of my life, but that all changed in February of 2008. I had shortness of breath and my fingers and hands were tingling. My family doctor thought the tingling was due to carpal tunnel syndrome since I repair computers and use my hands all day long, and he sent me to a pulmonolo-

gist for my breathing.

My lungs were fine, but I was diagnosed with Restless Leg Syndrome and a sleep disorder. After several months, I reminded my doctor that Porphyria runs in my family, and he referred me to a hematologist for testing. Though the tests were positive, the hematologist was not sure if I had AIP or HCP. Luckily, she sent me to Dr. Steven Shedlofsky, a Porphyria specialist and APF advisory board member two hours from my home in Lebanon, Ohio. I submitted the required stool sample and 24-hour urine in advance, and my wife and I drove to Dr. Shedlofsky's clinic.

Dr. Shedlofsky confirmed that I have acute Porphyria, but changed the diagnosis to VP because of the pattern of porphyrins. Since then, I have had several porphyria attacks, and received several series of Panhematin treatments.

At 55, I have learned not to take life for granted. I am thankful for the doctors who are treating me, I watch what I eat and am aware of the acute porphyria drug list. I will have my children tested for Porphyria, and I pray they don't have it. I know there is no cure for VP but I feel confident that I will be able to live a long and normal life even with the disease.

I look forward to hosting APF member meetings both at my house in Lebanon, OH, and at my adopted mother's house in Youngstown, and to hearing the stories of all who attend.

Carrying On the Gene Bennett Legacy

Monica Firchow launched an emotional project several years ago. She is writing a biography of her father, Gene Bennett, who had Congenital Erythropoietic Porphyria (CEP). CEP is one of the rarest forms of Porphyria, with fewer than 200 patients documented in the medical literature.

The book project got started when Monica ran an Internet search for information about her dad several years ago, and was stunned to find photographs of him on the websites of people she didn't know. The photographs illustrated his condition — the severe damage to his skin caused by the sun, and damage to the underlying cartilage and soft tissue that caused the loss of some of his facial features and eventually his fingers.

The book began as a means of "taking ownership" of the photos she had found. She decided to do that by telling his story herself.

Monica and her siblings remember the wild stories their father told about how he came to look the way he did. Although he had not in fact saved a group of children from a burning bus, and his left ear never did jump off his face and fly out the window, he had a way of making people comfortable with him, and of managing to live in the world while looking so different from others in it.

CEP is the second rarest form of Porphyria, so Mr. Bennett was a one-of-a-kind patient even for some Porphyria experts who treated him. Recognizing this, he "gave the last ten years of his life to

[porphyria specialist] Dr. Neville Pimstone," according to Monica, making himself a subject of study so doctors could learn more about the disease he feared would affect his grandchildren.

Monica's book is almost finished, and she has become a generous spokesperson and advocate for people with Porphyria, although she does not have the disease herself. She is an APF member, and has worked with us to educate doctors and the public about all types of Porphyria.



Monica maintains a website about her dad, www.genebennett.net, and last year joined Dr. Pimstone to talk about Porphyria on a radio station near her home in Atascadero, California. She hopes to repeat the radio show this year during Porphyria Awareness Week.

If you are interested in getting local media coverage for Porphyria, please contact Mira at the APF office.

Debra True: Married to an Ironman

Debra True was once a very athletic young woman. She and her husband, James, shared a love of the outdoors and a sport-filled life until Deb began to experience a variety of medical problems. She had endured abdominal pain since she was a youngster, but began to have several other vague health problems as a young adult. No matter how many times she went to the doctor, they could not figure out what was causing her symptoms.

When she did have these strange attacks, she suffered with intense abdominal pain that flared up often, and had the strange feeling that her legs were not attached to her body. They felt as if they simply were not there. Over time, both symptoms became severe enough to warrant a diagnosis, but as is typical for Porphyria patients, Deb could not find a doctor who could diagnose her. Then, after years of pain, her symptoms disappeared, and she had what she calls "a six year remission."

Unfortunately, the remission ended after her daughter's birth. This time, the symptoms returned with a vengeance. Once again, they were intermittent, which complicated getting a diagnosis. Then Deb became pregnant with her second child. After the birth, the undiagnosed illness intensified, and she suffered for seven more years. At times, she was wheelchair bound. Eventually, her dentist mentioned that she might have an acute Porphyria, and his hunch was correct — Deb was diagnosed with Hereditary Coproporphyrinuria (HCP). She soon discovered that other patients in her area had acute Porphyria as well. Instead of having a support group meeting to discuss their cases, they sometimes meet at their local hospital where they have Panhematin infusions together. Their's certainly ranks number one as the most interesting support network!

Deb's husband, James, has always been very supportive. In June, he will participate in the Ironman Triathlon in Coeur d'Alene, Idaho to raise money for the APF through the Janus Charity Challenge. Of his decision to take on this challenge, James writes:

I've watched Debra battle this disease every day and not give up. She has days when she's unable to get out of bed because the pain is so severe. Our two kids, Ryan and Amy, have watched their mother battle through her severe pain. Even when she is having an extreme attack, she tries to take care of all their needs. Debra is always trying to help others, too, and puts her own

needs last. I admire her for her strength because I know that she is suffering every day of her life. As her husband, there isn't anything that I can do to relieve her of her pain. But I can help in another way. On June 21, 2009 I will compete in the 2009 Coeur D'Alene Ironman. I am going to raise funds for The AMERICAN PORPHYRIA FOUNDATION, an incredible nonprofit organization that fights for a cure and treatment for porphyria. Every day, porphyria patients battle to beat this disease.

On June 21st my battle will be a 2.4 mile swim, 112 mile bike and a 26.2 mile run. My battle will end at the finish line but their battle will continue. With your help we can increase awareness and research for a cure. Please help however you can.

Just imagine the challenge involved in completing, let alone competing in, this famous race! I ask that you join me in supporting James's efforts by making donations to the APF through the Janus Challenge.

— Desiree

How the Janus Charity Challenge Works

- For any gift you make to the APF between now and June 20, Janus will donate an equal amount, effectively doubling the size of your contribution.
- Your \$50 becomes \$100, your \$100 earns us \$200, and so on.
- You can help us take advantage of the Janus Challenge in one of two ways:
 - 1) Mail us a check with "Janus — James True" in the memo field (we will let James know about your donation so he can keep his website up to date), or 2) Donate with your credit card at: <https://www.kintera.org/faf/donorreg/donorpledge.asp?ievent=280865&supID=240568713>
- Photo shows member Lauren Warren crossing the finish line for the APF at the 2004 Lake Placid, NY Ironman.



\$25 Million Gift for Boston Children's Orphan Disease Center

In a development to give rare disease sufferers and doctors everywhere cause for hope, Children's Hospital Boston last year received a \$25 million grant to found The Manton Center for Orphan Disease Research, the only center for orphan disease research in the world. An "orphan disease" affects fewer than 200,000 people in the United States. 6,000 orphan diseases have been identified so far, including the porphyrias.

Even at the breakneck speed of modern medical advances, rare diseases pose such severe challenges — in identifying research subjects, and attracting research funds — that our treatment options are sharply limited. Living with severe symptoms for years before finding a definitive diagnosis is the rule for rare disease patients.

Many rare diseases affect children. EPP usually causes its first symptoms before a child's sixth birthday. We are heartened by the Manton Foundation's generous gift to Children's Hospital Boston, because it demonstrates that serious donors are recognizing the importance of rare disease research.

Darlene Folkes: Learning to Live with PCT



Darlene Folkes developed easily recognizable PCT symptoms only last spring, but her problems started before that, with tea-colored urine, prompting her primary care physician to send her to a rheumatologist to be evaluated for possible lupus. While she was seeing the rheumatologist, her primary care physician became concerned about her gallbladder. While preparing to have her gallbladder removed, Darlene started getting a lot more exposure to the sun.

Wanting to lose a little weight and get in better physical condition before the surgery, Darlene started spending more time walking out of doors. In May of 2008, her PCT blisters started forming — prickly bumps on the backs of her hands that turned into half-dollar sized blisters and refused to heal. They were very painful and getting worse, prompting her doctors to consider some sort of sun allergy.

Finally, at an urgent care clinic, doctors did a smear of the blisters and sent her to a dermatologist. He did a skin biopsy, and diagnosed her with Porphyria Cutanea Tarda (PCT). Darlene is 44 years old, which makes her typical of PCT patients — the disease gets the name *tarda* (Latin for “late”) because patients usually do not experience symptoms before they are in their 40s.

Once she had a diagnosis of Porphyria, Darlene found out about the Mount Sinai Porphyria Clinic (in New York City, three hours from her home) through a friend of her aunt who had heard of Dr. Lawrence Liu, one of two doctors who staff the clinic. She describes meeting Dr. Liu for the first time as an almost revelatory experience, calling him “a breath of fresh air” for his compassionate bedside manner, and for being the first doctor she encountered who really understood Porphyria and took an interest

in all of its effects on her. Dr. Liu was also the person who let Darlene know about the existence of the APF.

Since then, Darlene has become an APF member, and has carefully followed Dr. Liu’s advice to avoid the sun while her blisters heal, and to avoid alcohol entirely. Dr. Liu also started her on low-dose chloroquine (taken in pill form), which has improved her symptoms somewhat. Dr. Liu did a biopsy of her liver, and fortunately found none of the tissue damage that can affect PCT patients.

In addition to blisters, Darlene had the hair growth on her face and legs characteristic of PCT. But the blisters on her hands were the worst part, because “you do everything with your hands,” making it easy to reinjure them, and hard for them to heal.

Darlene had surgery she believes could have been avoided with prompt diagnosis and treatment of her PCT, as well as prolonged symptoms of the disease, and the stress and grief of symptoms her doctors would not recognize. We wish Darlene a complete and speedy recovery, and hope her story will help someone else to a timely diagnosis.

Watch What You Read

Darlene Folkes describes tremendous gratitude at finding the APF last year, particularly for the comfort she found in the clearly explained, medically accurate information on our website and in our brochures. On first learning that she had PCT, she had sought out information on the Internet, and refers to some of the websites she found as distinctly “unhelpful,” with references to Porphyria as “the vampire disease” and to people “going crazy” with the illness.

The APF distributes medical information only after it has been approved by members of our expert advisory board, doctors who can speak authoritatively about Porphyria because they have treated patients and studied the disease over many decades.

Scandal, Intrigue, Hemophilia and Porphyria

Readers interested in the history of Porphyria will want to get their hands on a copy of *Royal Maladies: Inherited Diseases in the Ruling Houses of Europe*, a new book by medical historian Dr. Alan R. Rushton. Dr. Rushton’s book is divided into two main sections — one about hemophilia in the British royal family, and one about the supposition that King George III suffered from Variegated Porphyria. Rushton reviews evidence about other royal family members’ health, and discusses how these diseases were viewed 150 or more years ago.

Dr. Robert Desnick, Dr. Kenneth Astrin and the APF were all involved in the research for the book. The APF helped locate patients with VP, including some who believed they might be connected to the royal family. Drs. Desnick and Astrin did the DNA testing in the Mount Sinai Medical Center genetics lab.

So if you just can’t get enough of those royals, if you have purchased a copy of the King George letter from the APF and want to understand more of the history surrounding its writing, or if you’d just like to have a clear and readable account of this investigation into medical history, this is the book for you!





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

Updated Member Stories Section: Full-length versions of the member stories in our newsletter.

Have you ever been given Panhematin or IV glucose for porphyria? If so, you should have received an important research questionnaire from us. Thank you for taking the time to fill it out.

Tell your doctor about the **Drug Safety Database for Acute Porphyria** at www.apfdrugdatabase.com/ and see page two of this newsletter for more physician education materials.

Is Your Membership Up to Date? Stay current on 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: 713-266-9617 or 866-APF-3635. *Thank you.*

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