American Porphyria Foundation

3rd Quarter, 2008

A Gift of Friendship and Education

Over the past year, we received a number of requests from physicians around South America asking us to facilitate educational meetings about porphyria diagnosis, treatment, research efforts, molecular studies and the research and treatment horizon. Fortunately, several of our APF members were interested in beginning educational efforts in South America and provided the funding to make these meetings possible. With their help, we hosted two educational presentations in São Paulo, Brazil — at the University of São Paulo and the Albert Einstein Hospital. We also initiated collaborative efforts with both hospitals on testing patients' families for porphyria, conducting research and producing publications. We are grateful to **Dr. Karl Anderson** (l) and **Dr. Robert Desnick**, who presented their findings to the meetings. Standing-room-only audiences gathered to hear them.

Porphyrias: Clinical Features, Diagnosis & Treatment
Karl Anderson, M.D., FACP
University of Texas Medical Branch
Porphyria Center and Porphyria Laboratory
(409) 772-4661
Testing and clinical consultation for all the porphyrias

Porphyrias: Molecular Genetics and Diagnosis
Robert Desnick, Ph.D., M.D.
Mount Sinai School of Medicine
Porphyria Center and Molecular Porphyria Laboratory
(212) 659-6779 porphyria@mssm.edu
DNA testing for AIP, HCP, VP, f-PCT, EPP, CEP

Many people worked together to make the meetings in São Paulo a success. I'd like to thank Dr. Eder Quintão and Dr. Marie Soule from the University of São Paulo for facilitating the first lecture. Brian Sanz of Dynamic Pharma Group, the distributor for Panhematin in Brazil, attended the presentations and made it possible for Dr. Ricardo Villareal to attend from Colombia. Dr. Villareal and his wife are both physicians. They recently founded a Colombian patients' organization and joined our *Global Partners* association. In Brazil, Ieda and Benie Bussman assisted us in locating doctors who would be interested in learning more about porphyria. Dr. Charles Lourenço, the first physician in South America to be selected for our *Protect the Future* program, also attended the meetings. Dr. Lourenço is in training with Dr. Anderson to become a porphyria expert. His training is a wonderful thing for South American patients and doctors as they will some day have a porphyria expert closer to home. Monica Bocaiuva coordinated all of our activities and gave us a terrific tour of the city. Patty Wood, a Pulitzer Prize nominated photographer and Dr. Anderson's wife, chronicled the events through her wonderful photographs. See them on our web *Image Gallery*.

Next, we were off to Buenos Aires, Argentina to meet Dr. Alcira Batlle, who heads the *Centro de Investigaciones Sobre Porfirinas y Porfirias* (CIPYP) at the University of Buenos Aires. When we arrived, Dr. Batlle and her husband, Carlos, were there to meet us and drive us to our hotel. Dr. Batlle informed us that we had missed an airline strike by only two hours, so we were even more grateful for her "watching over us." The next day, we met Dr. Battle for a tour of her Porphyria Center, which included meeting the porphyria team, many of whom have been working together for decades. We were surprised with a luncheon attended by several porphyria patients. Over delicious empanadas, we discussed how they might form a patient organization like the APF, and how they can help Dr. Batlle and her colleagues enhance porphyria awareness and education in Argentina. Rafael de la Torre shares his PCT story in the *Global Partners* section of our website and encourages others in Argentina to contact him at rdelatorreu@hotmail.com about creating a porphyria group.

News From the Director... The APF is delighted to announce that APF member **Dr. William McCutcheon** has joined our Board of Trustees. Dr. McCutcheon and his wife Irene have been supporters for years. We know that Dr. McCutcheon will bring the same kind of leadership and creativity to his new role on the Board that he employed to help expand our *Protect the Future* program to include the Mount Sinai Hospital Porphyria Center. We look forward to Dr. McCutcheon's continuing role in the APF's growth and success. ***— Desiree***

APF Aids Porphyria Research

In July, the APF awarded **Prof. Peter Meissner** of the University of Cape Town Porphyria Unit a grant to attend the Gordon Research Conference on Tetrapyrroles (i.e., porphyrins) in Rhode Island. This grant is part of our ongoing support for research into the science behind the porphyrias, their treatment and a potential cure.

Prof. Meissner studies how the chemistry of porphyria relates to patients' experience of the disease and doctors' ability to diagnose and treat it. His scientific work has been enormously important for understanding and diagnosing Variegate Porphyria, one of the most common inherited diseases in South Africa.

Porphyria work at the University of Cape Town (UCT) began in the early 1960's. When Prof. Meissner arrived there, he worked with Prof. Lennox Eales, the man who trained our own Dr. Neville Pimstone in the porphyrias. Porphyria patients in Cape Town are seen in a dedicated clinic at Groote Schuur Hospital, famously associated with the world's first heart transplant.

The diagnostic laboratory in Cape Town gets requests for porphyria diagnosis from approximately 500 patients each year. Typically, 100 of these people have porphyria, with Variegate Porphyria making up ±48%; PCT, ±39%; and AIP and EPP occurring more rarely. The clinic sees about 100 patients each year.

For a time, Prof. Meissner worked at the University of Georgia with Dr. Harry Dailey, a respected porphyria expert. Following his return to Cape Town in 1993 he identified the mutation responsible for 94% of VP in South Africa, linking this mutation to a "founder family," a Dutch couple who were married in Cape Town in 1688.

Prof. Meissner's work revolves around improving diagnosis in South Africa; understanding why some people with a porphyria gene mutation have symptoms while others do not; the relationship between PCT and Hemochromatosis, Hepatitis C and HIV; mutations in VP; EPP in South Africa; and developing a mouse with VP to help better understand the disease and develop a cure.

Prof. Meissner writes: "I have no doubt that our work and research will continue to thrive — in the interests of better understanding and treatment of porphyric patients the world over. I assure you that an offer of such funding is not taken lightly and greatly appreciated. I consider it a privilege to be associated with your Foundation and commend you for your efforts in educating and informing both the medical profession and the public at large about the porphyrias."

Atlanta Gets IN TOUCH

Debbie Puchkoris (HCP), an APF member outside Atlanta, Georgia, hosted a meeting at her home in the spring. Debbie's fiancé and daughter attended the meeting with her, and people came from as far away as Tennessee to attend.

Debbie showed the APF DVD, *Porphyria Live*, and porphyria expert Dr. Claus Pierach phoned in to be the featured speaker at the meeting. Debbie says of Dr. Pierach's participation: "it was so wonderful to talk with a doctor who was really into porphyria, it was like he couldn't do enough to help us." Indeed the APF could not exist without the selfless participation of Dr. Pierach and the other members of our Scientific Advisory Board. These men and women have given generously of their time over the past 27 years and have made themselves open and available to patients and local treating physicians.

Debbie had good things to say about the experience of hosting an In Touch meeting as well: "Talking with other patients and comparing notes and symptoms was really useful." This is an experience common to many APF members. Just like reading another member's story on the APF website, meeting with other porphyria patients for the first time and finding out that they share symptoms similar to the ones you experience can be revelatory. It's important to feel that the symptoms you're experiencing are real so that you can go to your doctors and get the help you need to resolve them. At the same time, as the experts always tell us, porphyria patients can have symptoms that are not due to the disease. So it's important to consult your doctor about any troubling symptoms you experience so that she or he can take the best care of your health.

Get IN TOUCH In Your Hometown

Would you like to attend an IN TOUCH meeting near your home? Often the best way to do that is to host one yourself, and it's easier than you think. Call the office at 1.866.APF.3635 or email Mira <miraapf@gmail.com> for more information.

The APF can help facilitate a meeting by supplying materials, handling invitations and providing a speaker whenever possible. We can help you find a venue and other activities for your meeting, and we're here to answer any questions you may have about what hosting entails.

How Many People Have Porphyria? Why Do We Need to Know?

Have you ever been asked, "How many people have porphyria?" Unfortunately, no one knows. Yet having a reliable answer is very important.

The people who make government grant funding decisions often want to know how many people are affected by a disease before they decide to give money to support research or other projects benefiting patients. So finding out how many people in the U.S. have porphyria is vital. Yet porphyria, like other rare diseases, receives very limited funds from government sources. And without government grants, we do not have the resources to make major advances in diagnosis and treatment like building a registry of porphyria patients. It's a vicious circle.

Together, we can do something about this. We ask that you begin by asking every family member or friend who has porphyria to contact the APF. We have begun the initial steps to create a national porphyria patient registry and determine the incidence of each type of porphyria. When we have collected these numbers, we can pass them on to experts and they can extrapolate how many people across the country have the disease. Although we would like everyone to join the APF, our registry project is not related to membership.

Not only do grantors look at the number of people affected by the disease, there are two more steps in the grant process. First, the grantors have explained that applications have a much better chance of being funded if the people affected are willing to make some contribution to the work for which we are requesting government funds. This contribution is our way of showing, as porphyria patients, that advancing work on our disease is a priority for us. This is why you recently received a letter asking for your help for "matching funding" or our NIH grant applications. **Many members joined in this "matching" campaign and thanks to your generosity, we are close to reaching our goal. We are deeply moved by your support and we thank you.**

There is one more step in the grant process. We must also encourage individual members of Congress to support our efforts for funding from the National Institutes of Health (NIH) and to add "appropriations language" to fund porphyria in next year's budget. This is not as difficult as it sounds. Each representative has a "legislative health aide," who assists with medical affairs. The APF can provide you with the information they need to move forward in the granting process. To contact your Representatives and senators: **http://www.house.gov/** and **http://www.senate.gov/** **REMEMBER: THEIR JOB IS TO HELP YOU!**

In Memory

We are saddened to hear of the passing of our dear friends at the APF. Some of their friends and family have chosen to make a gift to the APF in their memory. We sincerely appreciate their thoughtfulness and desire that their memorial help others with the disease as follows: Dolores M. Brazas for *Wesley Brazas*; Diane Levere for *Dr. Richard D. Levere;* Marianne Bonyhady for *Kalman J. Bonyhady;* Ada Trilling for *Len Caplan;* Sylvia Luehrs for *Marvin Luehrs;* Monica Firchow for *Gene Bennett;* Vanessa Strange for *Robert McMillen;* Michael Kaiser, Susan Bonner, Terri Burke, Susan and Charles Allen, Josephine Busa, Jodi Danyluk, Cynthia Zalesky, Joanne Wood-Ellison, Marianne Schmidhoffer, Sandra Roberts, Shannon Parks, Thomas O'Connor, Kim Lucy, Susan Hyde, Eric Hall, Martha Falcon, Josephine Dusvitch, Henrietta Diaz, David Campos, and Marie Rodriguez, Melanie Davis, Veronica Johnson & Peter Zuckerman for *Ian Maynard;* Desiree Lyon Howe for *Dr. Richard Levere, Dr. Shigeru Sassa* and *Dr. Rudi Smidt;* John and Evelyn McArdle and Donna Lentol for *Patsy Brady.*

In Honor

The following people have honored their friends through a gift to the APF: Elizabeth Adams for *George Pullen;* Edwin Rumsey for *Bruce Pegelow;* Sharon Koch for *Terri* and *John Liguori;* Michael Kaiser for *Amy* and *Steve Maynard;* Desiree Lyon Howe for *Drs. Steven Shedlofsky, Karl Anderson, Robert Desnick, Claus Piearch, Montgomery Bissell, Joseph Bloomer, James Kushner, Neville Pimstone, Micheline Matthews-Roth, Maureen B. Poh-Fitzpatrick, Peter Tishler, Herbert Bonkovsky.*

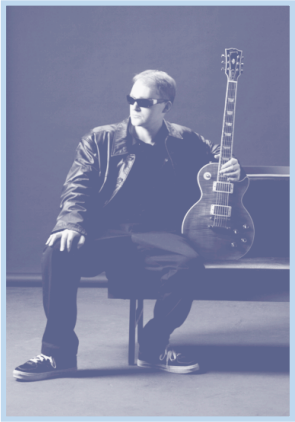
We Will Miss You, Patsy

Anyone who ever spoke with Patsy Brady knew the feeling of "love at first hearing." Patsy was a cheerful woman with a beautiful Irish accent — beloved of her family, friends and the APF members and staff who were lucky enough to know her.

Patsy died of cancer, which was diagnosed in tests run to find the cause of her abdominal pain after a visit to the Mount Sinai Hospital Porphyria Center in New York.

Patsy was a longtime APF member who both supported our work for years and welcomed other APF members into her home through the In Touch network. Patsy was also the very first patient at the Mount Sinai Porphyria Center when it opened its doors several years ago.

We are saddened by the passing of Patsy and other APF members and friends, and pray strength for their families.



Live & in Concert

When APF member **Jon Jones** took his band on tour this summer, we used the ENews to help him publicize it. Jack Jones and his wife Mary saw the announcement and decided to drive their motorcycle the 60 miles from Sweetwater, TN to attend the concert in Knoxville and meet Jon.

Both men enjoying meeting each other and sharing how porphyria had affected their lives and how they deal with its symptoms, which Jack described as "wearing him down completely."

Rediscovering the motorcycle was Jack's coping mechanism. When the pain is bad, he takes a long ride or tinkers with his bike. Jon, of course, has his music — playing and writing to cope with his illness. For Jack, the meeting with Jon was timely, because his bouts of pain and sickness had left him depressed. He needed the encouragement Jon gave him and vice versa. Their meeting exemplified why the APF instituted our In-Touch Network: to provide our members an avenue to meet and learn from one another. Everyone comes away encouraged!

Attention EPP Patients!

Don't forget to have the following tests annually: a fractionated red cell porphyrin test,* a complete blood count and blood chemistry panel including liver chemistries such as bilirubin, SGOT and SGPT. In an occasional patient, protoporphyrin causes liver problems, so monitoring liver function is important.

Always discuss your diagnosis and testing with your doctor, and see our website for more information: **http://www.porphyriafoundation.com/about_por/types/types08.html**

Clinuvel Pharmaceuticals has been granted Orphan Drug status for afamelanotide (the CUV1647 we wrote about in the last newsletter), a potential new treatment for EPP and CEP. The hope is that afamelanotide injections will make skin less susceptible to painful photosensitivity. Please watch our website and the ENews for updates.

**Dr. Micheline Mathews-Roth has informed us that many labs are cutting out the FEP test, but that the fractionated red cell porphyrin test is a better option anyway. Mayo Medical Labs will perform this test.*

Ann Warnke: Living with EPP

Ann Warnke first noticed symptoms of EPP when she was 13 years old. A family friend took Ann and some other kids deep-sea fishing, and after she got home that night, her face swelled up until she couldn't open her eyes and her nose disappeared. The capillaries under her skin burst too, so that in her own words she looked "like I'd been beaten."

Her doctors first thought the swelling and bruising might be a bad reaction to food she had eaten, and Ann had many more photosensitive incidents like this before she was diagnosed with EPP as an adult. Fortunately, her own experience allowed Ann to have her younger son tested when he first showed symptoms at the age of three. Like Ann, Matthew was out on a boat when the sun burned his skin to the point that holding a hot dog was painful and his ears turned inside-out from the swelling.

These days, both Ann and Matthew have their EPP well under control. With the right protection, they can even go skiing or take a cruise. For both of them, a photosensitive reaction with EPP means swelling, itching and painful burning that can take up to five days to subside. During that time, the Warnkes turn the A/C down low and use ice bags, Benadryl and prescription medications to ease the discomfort.

Ann has been taking pharmaceutical grade beta-carotene — first as the prescription drug Solatene and now as over-the-counter Lumitene — to reduce the symptoms of EPP for many years. At home, she prefers to cover up with a facemask and umbrella and avoid spending time outdoors in the sun. She finds that Lumitene turns her skin orange and gives her gastrointestinal upset when she takes it over a lengthy period. So she begins taking Lumitene a few weeks before leaving for a vacation, continues through the vacation, and then tapers off it after she comes home. She still covers up all the time, but she is able to tolerate more time in the sun with the medication and appreciates that freedom.

Back home, Ann has special tinting on her windows to protect her from the sun's UV rays. APF Scientific Advisory Board member Dr. Micheline Mathews-Roth helped Ann with the window tinting and has gotten testing information to Ann's doctors. Ann calls Dr. Roth "just phenomenal, extremely good and accessible." Dr. Roth has been a wonderful resource both for the APF and for EPP patients.

Talking to Ann, I feel as if I'm talking to a longtime friend, though we've met in person only once. She is wonderfully positive and a pleasure to know.

Ann will host an IN TOUCH meeting at her home in Houston on Saturday, October 18. Contact the APF office for details.

— Mira Geffner

The APF is a non-profit organization, and members are our most important means of support.
If you are not a member, please join.
If you are a member, please help us by keeping your membership up to date.
Thank you!

Chicago Gets IN TOUCH

At the end of July, APF member Dee Bruno and her family opened up their home outside Chicago for an APF IN TOUCH meeting. Dee's son Mike had prepared a lunch, and we got to know each other a bit and share our porphyria stories.

One woman there told us about receiving a liver transplant after her own liver was severely damaged by EPP. She has had a kidney transplant as well, after anti-rejection drugs for the new liver caused kidney damage. Unfortunately, nothing alleviates her photosensitivity but covering up and staying inside. This kind of case makes the search for a new treatment for EPP especially urgent.

After lunch, we sat down to our telephone question and answer session with APF Scientific Advisory Board member Dr. Steven Shedlofsky. Here is some of what we learned:

- The APF Scientific Advisory Board members are happy to consult with physicians on managing porphyria. Dr. Shedlofsky suggested porphyria patients ask their doctors to contact a porphyria expert for guidance on diagnosis and treatment.
- Even a child as young as 4 years old who shares his mother's AIP gene mutation should avoid the drug groups for which there is a long history and much of evidence of danger, like sulfonamide antibiotics (sulfas or sulfa drugs) and barbiturates. Even though most people who inherit a gene for acute porphyria will not become sick with it, experts don't know yet how to predict who will be lucky and who will not. So it is important to be cautious with fairly universal triggers.
- It is impossible to diagnose porphyria without the right tests of urine, stool, blood and/or plasma, and knowing which porphyria a patient has is vital for proper care. Differentiating between PCT and VP or HCP is a great example. Some of the symptoms seem similar, but while phlebotomies and low-dose chloroquine can induce a remission of PCT, they will do nothing for VP or HCP. In PCT, it is not necessary to worry about using medications dangerous to acute porphyrics.
- It always bears repeating: porphyria patients should eat a healthy diet high in carbohydrates, keep to more complex carbohydrates like fruits and whole grains and avoid free sugar (e.g., in sodas). Porphyrics should never fast, and those who can should follow a healthy exercise program.

Struggling With Porphyria When Your Husband Is In Iraq

About four years ago, I started having abdominal pain. It was like having a hot iron stab me in the abdomen followed by an elephant sitting on top of it. I kept going to the Emergency Room, but my lab results were always normal, and I was told there was nothing seriously wrong.

Before I was diagnosed, I had an ileostomy and then developed pancreatitis. Still none of the doctors could diagnose me. One morning, a new GI doctor mentioned that my urine and the ileostomy were both a strange reddish color. He asked if I had eaten anything that could cause that, then ordered more tests and said that there was nothing left to do.

Eventually, doctors reversed the ileostomy and took out my gall bladder, thinking that would fix the pancreatitis. When I still had horrible pain, my doctors decided I was depressed, prescribed antidepressants and sent me home.

Since I am a nurse, I looked into my records and showed the test results to the doctor who told me I had porphyria. I read about it on the APF website and what I read described my entire family perfectly.

My regular internist didn't believe I have porphyria because it is so rare, so when I was ill I just went to the ER where I worked. Together, my colleagues and I strove to find a treatment that worked.

I began to improve when they put me on Panhematin, but still had a crisis every time I had a menstrual cycle. Eventually I started getting Panhematin as soon as I had symptoms, and we broke the cycle of attacks. I stayed out of the hospital for one month, then two. My goal is to be out of the hospital for three months straight.

I have God's greatest gifts: a wonderful husband, Edgar, precious children and a great extended family. When Edgar came into my life, he brought hope and help and love. He keeps me fed when I am sick and handles my many needs. And my being sick has helped my children grow into compassionate, capable young people.

Now Edgar is in Iraq, and it's hard without him. I miss him, and each time we talk I am afraid that it will be the last.

I love him and miss him. I am proud of him. It's hard when he's away because when I am ill I can't advocate for myself and things fall through the cracks.

Now I teach in-service for the hospital using the slides on the APF website. You can also have a nurse or a doctor in your hospital use the slides to teach their colleagues. I tell the staff to put a face on each condition they learn about, because they may have a patient who suffers from it.

You, too, can be a teacher. I encourage you to learn as much as you can about your type of porphyria and start by teaching your own doctor. ***— Waddie Vazquez***

Happy 25th, Panhematin!

On July 25 Ovation Pharmaceutical celebrated the 25th birthday of its product Panhematin. It was a big day for acute Porphyria patients too, and I spoke to the Ovation home office staff to help them understand what their product means to a person living with Acute Intermittent Porphyria.

When I was first diagnosed with AIP in 1995, standard practice was still to administer glucose for 24 hours to try to resolve an acute attack before using Panhematin. I think that's part of why even though I was diagnosed by the end of my first attack, I wound up in much greater danger during my second severe attack. I rapidly advanced from blinding pain, to hyponatremia and disorientation, to a grand mal seizure. By the time I received heme, I was in the ICU and unaware of my surroundings.

After that second awful attack, I kept muddling along with AIP for a couple of years, having minor attacks pretty much every month, but not going in for treatment. It was a bad situation, but I was still a little too stunned by my diagnosis and what it meant to do much about it. My quality of life eroded steadily as I started cutting back my hours at work and taking more sick days. I dropped my athletic activities and started cancelling travel or social plans regularly because I was sick. I just couldn't get my life back to normal.

A lot has changed since then. These days when I feel the escalating belly pain that is always my first sign of an attack, I call my hematologist and he orders a series of Panhematin infusions and IV Dextrose for me at the hospital infusion center. I get treated as an outpatient, which is lovely as it allows me to sleep in my own bed at the end of the day and keep up with more of my normal life. I usually have three or four infusions per attack.

Obviously I would not have planned to live exactly like this — visiting my local hospital four days out of each month for the forseeable future. But I try not to think about it that way. I have active acute porphyria, and until the disease eases up or we find a cure, I depend on Panhematin for my quality of life. Now when I get sick, I can make a good guess about when I'll feel better. I recover more quickly from attacks than I ever did without treatment, and that means getting back to my life sooner. During good months, I can forget about having AIP for a week or two.

I remember several years ago when I went in to the hospital for an infusion and the pharmacist came out to warn me that I was using one of his last three or four vials of Panhematin and he wasn't sure when he'd be able to get more. Manufacturing issues caused a temporary interruption in the Panhematin supply — this was before Ovation acquired the drug. After those three or four vials were gone, I had a pretty unpleasant attack that dragged on but luckily did not become dangerous. After that attack, my husband and I went home and started talking about where in the world we could move — someplace where he could work and I could be treated when I got sick.

So I'm very glad that Ovation's interests have dovetailed so nicely with those of acute porphyria patients. Ovation's commitment to supplying Panhematin and educating doctors about its use, and to supporting the APF's educational efforts, is a very good thing for porphyria patients. So thank you, Ovation!

— Mira Geffner

Longtime Member Joins APF Staff

I am very pleased to announce that after more than 10 years as an active member of the APF, Mira Geffner is joining our staff as Development Director. As an APF member, Mira has hosted and assisted with patient meetings, participated in the first international patients' conference on the porphyrias in Rome, spoken to the staff of Ovation Pharmaceutical about being an acute porphyria patient and worked to advance the cause of research and treatment of porphyria.

Mira was diagnosed with Acute Intermittent Porphyria during her first attack 13 years ago. Since then, she has participated in two clinical studies conducted by Doctors Anderson and Bonkovsky. When she is healthy, Mira enjoys cooking, hiking and knitting, and she can recall the lyrics of a pop song or Broadway show tune to fit almost any occasion. Mira lives with her husband Paul in Los Angeles.

Mira in N. California, before her diagnosis.

Mira looks forward to meeting every APF member in her new role: coordinating the In-Touch Network and APF outreach at medical conferences, editing the newsletter and working on the website in addition to developing our fund raising strategy. Please feel free to email Mira at miraapf@gmail.com and say hello — she'll be happy to hear from you.

— Desiree

HCP Hits Mother and Son

On the night of December 23, 2002 the phone rang. Earlier that year my mother had been diagnosed with Hereditary Coproporphyria, after years of misdiagnosis. Now her doctors said I should be tested as well. And then they confirmed our fears: I had HCP.

Not long after my diagnosis, we started hematin treatments. During these months of treatment, my mother and I shared some of the best and worst times of my life. I remember laying in her bed early one morning watching Animal Planet, a mother polar bear caring for her cub. Every so often she would reach over and squeeze my hand lovingly. I also remember watching helplessly as my mom lay in the fetal position on the couch crying from pain, knowing I couldn't do anything to help. The same happened to me frequently. We each understood what the other was feeling and it frightened me.

One morning in June, I remember my dad saying goodbye to my mom and me, and he was off to work. I was in the kitchen when I heard her fall. When I got to her room; she was lying on the floor unconscious. I lay there with her until the paramedics arrived. She passed away en route to the hospital.

The months after were hard and some days still are. I remember being sick and sad, but mostly it was all a blur.

In January of 2003, I felt well enough to visit my friend Heidi in Seattle. I fell ill soon after arriving there. Intense pain, severe nausea and lack of energy engulfed my body. Heidi's mother insisted on taking me to the hospital, where the doctors found me with a 105-degree fever and barely breathing. My lung and port were both infected. I was told later that I had come very close to death.

I decided to stay in Seattle after leaving the hospital. I had my ups and downs for a year or so, but in 2006 felt well enough to enter Seattle Central Community College and to start work on a political campaign. I worked amazingly long hours but enjoyed every second of it, because at last I was healthy. ***— Brad Crelia***

Beware the miracle cure!

The prospect of a miracle cure for a serious illness — take two pills every day for six weeks and your problems will be no more! — can be seductive. Especially on those days when you never want to see another doctor, or the inside of another hospital room; or when you wish that just this once you could enjoy a day at the beach with your kids, or decide what to wear without worrying about protecting your skin from the sun; or when the pain in your gut has become simply intolerable … on days like those it can be awfully tempting to believe claims that a miracle cure for porphyria might exist.

Unfortunately, it doesn't.

We remind patients and families dealing with pophyria that all treatments are best discussed with and prescribed by your doctor. The community of experts treating the porphyrias publishes treatment updates periodically, and we can help keep your doctor up to date. Just send us your doctor's name and address, and we'll keep them informed as new findings are issued. APF Scientific Advisory Board members (the experts who approve all of the medical information we distribute) are also available for consultation with your doctor when necessary. Chances are that if your doctor can't find solid medical/scientific information about a treatment you've heard mentioned, it won't do much for your health and may even be harmful.

The best contribution APF members can make to a cure for porphyria is one that supports the scientists and doctors working toward this discovery. That means donating money or time, or even participating in a research study when you can. To find out what you can do to get involved, give us a call!

Please Help Us Complete Our Match!

For the first time, the APF has a chance to help our experts move us closer to a real cure. Many of you have already contributed generously to help us reach the $100,000 goal we wrote about several months ago, and we thank you. We ask the rest of you to look into your hearts and help us meet this goal we all share. Raising this money will put our doctors in position to:

- **Continue and expand on training a new generation of porphyria experts;**
- **Build a network for better porphyria diagnosis and treatment;**
- **Share research for a cure for all the porphyrias;**
- **Build a national porphyria patient registry — we will finally know how many people in this country have porphyria and what type, how they are being treated and so much more.**

We are nearly there. Please send in a check marked "grant," or call me or Mira at the APF office to find out more. Working together brings us closer to our cure!
— Desiree

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.

What's New at the APF
www.porphyriafoundation.com

National Porphyria Patient Registry: The APF is 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 4 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.

Do We Have Your Current Email Address? Please take a moment to update your contact information by emailing porphyrus@aol.com or calling the office at 1.713.266.9617 or 1.866.APF.3635.

American Porphyria Foundation
4900 Woodway, Suite 780, Houston, TX 77056

Address service requested

NONPROFIT ORG.
U.S. POSTAGE
PAID
HOUSTON, TX
PERMIT NO. 7279