



## APF Benefit Fun Run: Orlando pitches in for a cure

Hats off to Grace Warfield, an APF member in Orlando, who single-handedly organized a fun run and raffle to raise \$1100 for the Foundation. Thanks so much, Grace. Your efforts are an inspiration to all of us. Plus, the money you raised will help our experts in their search for a cure for porphyria.



Grace planned the 10k/2mile run through the Track Shack Foundation, then coaxed local businesses into providing an APF banner for her booth, printed posters to advertise the run, and t-shirts bearing the signature "Team Porphyria" and the APF website address.

Grace's advice to other members wanting to put a similar event together: "Give yourself more time!" Except for the help she got from the Track Shack Foundation, Grace organized the run and raffle herself.

She did all that in only a month, minus the week she lost to a porphyria attack. But Grace remains unbowed and is planning to give the run another go for next year's **National Porphyria**

**Awareness Week**. For next year, she's planning to give herself at least three months to organize the event. Hopefully, other members and friends in the Orlando area will contact Grace and help with the event. Grace needs you!

Grace would like to thank: Ashley at the Track Shack Foundation; Don Snyder at Allegra Print & Imaging, who donated the banner and publicity signs; Tom Pitman of Pitman Graphics, who made the t-shirts; Joshua Boesch for his time, dedication and hard work; Family and friends who donated items for the basket; all the runners; and everyone who bought raffle tickets and cheered her on to a victorious day!

Contact the APF office to find out about buying a Team Porphyria T-shirt. Grace has one; her whole treatment team has them. Get one for yourself, or get several for the whole family!

You might want to know that Grace has also made a major impact on her medical team by educating them on AIP and keeping them abreast of treatment news, experts and recent journal articles. Thanks again, Grace, from all of us.



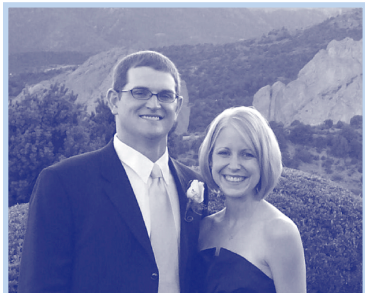
## Porphyria Awareness Week 2008 A Big Success

Thanks to you, our members, this National Porphyria Awareness Week was the best yet. Members pulled off some exciting achievements. We would like to hear about your efforts. The following are only a few:

- **Nita Busby** hosted an IN TOUCH meeting in California; the **Britton/Sasso Family** held a meeting in Iowa; and **Debbie Puchkoris** held a meeting, at which **Dr. Claus Pierach** was the featured speaker.
- **Lauren Warren** appeared on *Mystery Diagnosis*, the *Montel Williams Show* and *The Learning Channel*.
- **Desiree** took part in a radio press release about Awareness Week that was heard around the country.
- **Many APF members** hosted seminars in hospitals around the country.
- **Monica Firchow** and **Dr. Neville Pimstone** aired a radio show about porphyria in California.
- **The Healthwell Foundation** published a press release and **Ovation Pharmaceuticals** sent out more than 25,000 announcements about Porphyria Awareness Week.
- **Desiree**, **Dr. Robert Desnick** and **Dr. Karl Anderson** visited the **FDA Orphan Products Development** office and **Office of Rare Diseases** in Washington to urge attention to the needs of porphyria patients.
- **Dr. Shedlofsky** and the **University of Kentucky** created education programs.
- Newspapers in **Houston** and **Galveston** printed stories on **Dr. Karl Anderson** and his porphyria work.

See inside the newsletter for more exciting details. ...

## **“Sometimes people just have to live with abdominal pain”**



I first went to the hospital with disabling pain in my belly and lower back in August, 2005. Over the next year I would have episodes of severe pain, out of control blood pressure and heart rate, and very low sodium. Because I was too sick to eat, my weight dropped to 90 lbs. at 5'5. I was

diagnosed with everything from kidney stones, to a “paralyzed stomach,” to possible Crohn’s disease. I even had my gallbladder removed, and yet all the MRIs, CAT scans, ultrasounds and colonoscopies showed normal results.

By July 2006, I began having panic attacks and anxiety. My doctors thought I was a drug seeker and one doctor told my family, “Sometimes people just have to live with abdominal pain.”

That was a terrible day. I knew I wasn’t making this up...or was I? I began to question myself. Then a doctor friend of my husband’s suggested that I be tested for Porphyria. After a year of illness and more than a week in the hospital, my gastroenterologist ordered a 24-hour urine test and discovered I had porphyria. The symptoms weren’t all in my head after all! My family and I were thrilled to have a diagnosis!

We began treatment immediately. I had three days of Panhematin treatment and was released two days after that. It’s taken me about a year to regain the weight I lost and get back to my old self. I still have symptoms. However, now I call my new GI physician when I am on the verge of an attack, and I get Panhematin infusions right away as an outpatient.

Because I was adopted, we had no way of knowing that AIP was in the family. I would hate for anyone to go through what I did when a simple test could prevent a lot of pain. My family and I are determined to educate physicians we meet about the signs and symptoms of porphyria in the hope that this will help get someone else diagnosed quickly. — **Kirsten Crook**



### **LYON’S SHARE**

*It really is true that a mighty river can start with ONE RAINDROP. Our members have started a river with their single raindrops. Stories like the ones you are reading in our newsletter are proof that our members can reach out to the public and the medical community and make an enormous impact on porphyria awareness and education. In the last few months, APF members have held hospital seminars, hosted dinners for doctors, been featured in local and national major television series and press, aired press releases featuring porphyria, held races and so many other achievements. Big or small, they are all important and effective. God Bless you for your wonderful work and for the help and encouragement you have given to Yvette, Elizabeth, Carol, Sarah and me.*

## **Watch for the Ladies’ Home Journal**

For Porphyria Awareness Week, I spoke with a reporter from *Ladies’ Home Journal*. We talked for a long time about when my symptoms began and what it was like being sick for so long without a diagnosis. I was sick for 12 years and had 13 unnecessary surgeries, the last one a complete colectomy, before being diagnosed with Acute Intermittent Porphyria. The magazine contacted the doctors involved in my diagnosis and treatment. I really wanted to get across the frustration that many of us suffer dealing with a rare disease. Doctors don’t often think to test for porphyria. Often no one believes that we are sick, and we wait a long time to find out what is wrong with us.

What my husband and I went through before getting my diagnosis, and what we are going through now with my brother being very ill, is just terrible. Even though I have had genetic testing to prove that I have porphyria, my brother was treated like a drug-seeking nut case for the longest time rather than simply being tested for AIP. That is exactly the same thing I went through before my own diagnosis.

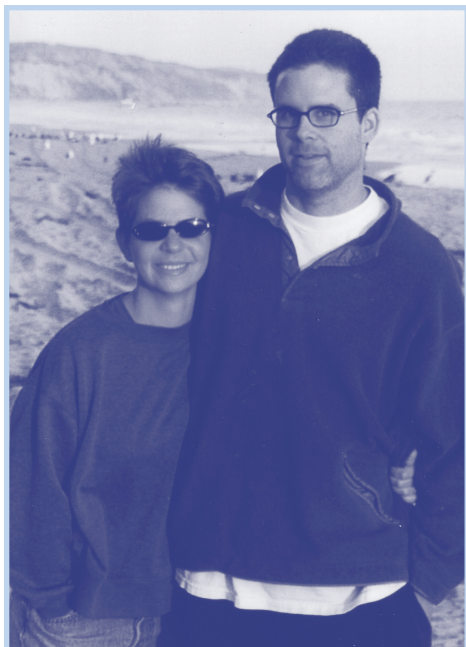
Before I knew I had porphyria, I never took any pain medications, because drugs scare me. Yet for years, I was treated as if I was in the emergency room seeking drugs. I can’t tell you how many doctors told me nothing was wrong with me and that my problems must be in my head. I really started to wonder about myself after hearing so many people saying the same thing.

I want to inform as many people as I can about porphyria and I want people to listen. When my story appears in the magazine and helps just one person, that is worth everything. I am also going to do an interview with a local paper here in Cleveland as well, and I just hope that my efforts will be able to help someone.

— **Judy Phelps**

*We will send out an ENews update with the publication date for Judy’s Ladies’ Home Journal story. If you don’t receive the ENews, just send your email address to [porphyrus@aol.com](mailto:porphyrus@aol.com).*

*Research is the Key to Your Cure!*



## **Myth: Only women can get sick with acute porphyria**

I am a very lucky person. I'm practically a poster-child for the benefits of sharing a porphyria diagnosis with your family members, and I feel my good fortune in having been tested and treated pretty much correctly from the outset. Unlike so many patients with Acute Intermittent Porphyria,

I've never had an unnecessary surgery, and I've been spared the awfulness of suffering attack after painful attack without knowing what was wrong with me. All that, and I had never heard of the disease before my first attack.

I inherited AIP from my mother, who inherited the gene from her father, who most likely inherited the gene from his mother. At least four women in my mother's family had been diagnosed with porphyria by the time I first got sick. So when I was admitted to the hospital with classic symptoms of an AIP attack — severe abdominal pain, GI troubles, tachycardia, severe electrolyte imbalance and eventually a seizure — my family network helped me get diagnosed quickly. My mother's cousin found out I was in the hospital, asked all about my symptoms, and told us what to have the doctors test me for. So while I was scanned and scoped to rule out more common conditions, my doctors started treating me with IV dextrose. Less than a week after I was released from the hospital, a few weeks after the start of my first attack, I found out for sure that I have AIP.

So the real question with me is: why didn't I know about the AIP in my family sooner? Because no men in the family had become sick with porphyria — and my mother and I were the first women to have inherited the disease from a man (my grandfather) — the family thought that only women could inherit and pass on the disease. This is a common notion, but it is false. While women do have more attacks than men do, the mutation that causes the disease is not sex-linked and there are men with AIP. Lucky me, I didn't suffer too badly from not knowing about my diagnosis before I got sick, and that is thanks to my family being around to give the doctors the information they needed to diagnose me while I was in the hospital.

Desiree always says of porphyria patients, "Those who know the most do the best!" This is true for undiagnosed family members too. Those who know the most have the best chance of safeguarding their own health and their children's.

— **Mira Geffner**

## **Madrid Porphyria Meeting**

At the end of April, porphyria experts came together in Madrid for a two-day scientific meeting. The occasion was the European Porphyria Initiative (EPI) second General Assembly and the European Porphyria Network (EPNET) Board meeting. Doctors came from South Africa, Argentina, and all corners of the EU to attend.

The doctors discussed updates to existing treatment protocols and the horizon for new therapies based on genetics and emerging drugs. There were also sessions on gathering and disseminating information among treatment centers, with special attention to epidemiological survey and drug data. The clinical sessions were grouped according to type of porphyria (cutaneous or acute); a third set of presentations covered biochemical and genetic diagnosis of the porphyrias.

International meetings at which scientists and clinicians can share their work are vital to the porphyria community. The porphyrias are so rare that it is difficult for researchers to spot trends either in the disease course or in patients' responses to treatment without pooling treatment data together. Having so many specialist laboratories in attendance provided an excellent opportunity to increase the knowledge of all the experts and help develop creative ideas in the field of porphyria.

**Visit the EPI website for more information:  
<http://www.porphyrina-europe.com>**

This is your newsletter, so kick in an article and make these pages your own! **To have an article printed in the next newsletter, submit it to us by July 1.** APF members would love to hear about your educational activities, diagnosis, treatment successes or anything you want to share that can help educate the porphyria community.

Each of you has a unique and interesting story to tell. So for all those times you have said, "I should write a book," well, now is your opportunity to start that book. If you don't have time or inclination to write your story, contact the APF. We will be happy to write it for you.





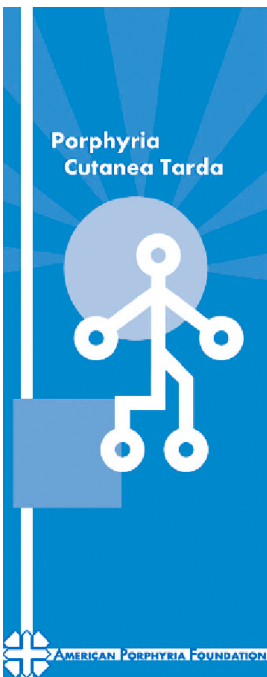
## New PCT brochure coming soon!

With many thanks to Dolores Brazas, the APF is delighted to announce publication of our updated brochure on Porphyria Cutanea Tarda. Mrs. Brazas has made this possible with a generous gift in memory of her husband, Wesley, who suffered from PCT. His wife wished to honor him by educating more doctors and patients about PCT.

PCT is the most common of all the porphyrias and the only type that can be acquired. Most PCT patients (80%) have acquired the disease, while the minority has inherited familial PCT. As its name indicates, PCT tends to develop in adulthood and primarily affects the skin, causing blistering of sun-exposed skin and possibly increased hair growth on and thickening of this skin. PCT patients may show abnormal liver function and may develop liver disease such as cirrhosis or cancer.

Eliminating disease triggers such as alcohol, estrogens and hepatitis C is an important first step in arresting a PCT crisis. A series of phlebotomies (removal of blood) to reduce the body's iron stores is the most common treatment. *PCT is the only type of porphyria for which phlebotomies are prescribed.* Low-dose chloroquine can also be effective, though normal doses of chloroquine can be dangerous, worsening the disease and causing liver damage.

The intricacies of managing PCT make it imperative that the APF place accurate information in the hands of treating physicians. Nearly all patients will achieve a remission of the disease after appropriate treatment and will go on to live free of PCT symptoms for the rest of their lives. Putting a member gift to such immediate and effective use is very gratifying for us at the Foundation. We thank you, Mrs. Brazas, and the individuals and families affected by PCT thank you, too.



## IN TOUCH in Iowa

For the first time ever, **Elaine Sasso's** granddaughter, 12-year-old Elizabeth, met other porphyria patients face-to-face when Elaine hosted an IN TOUCH meeting with her daughter and son-in-law, **Andrea & Larry Britton.** Elaine reports that the meeting was a wonderful opportunity for her granddaughter to meet and talk with



other porphyria patients and to speak in public about how she manages her photosensitivity. This was especially nice, because one of the attendees was an 11-year-old boy. He and his parents had driven several hours to attend the meeting. Children with porphyria have a special burden as they try to adjust to the world around them while dealing with a serious illness. It was great for the kids to have a chance to talk with each other.

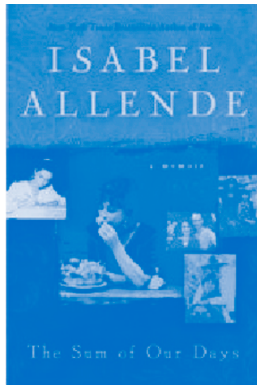
Elizabeth gave a presentation about some of the special sun-protective clothing she wears and about the accommodations her school makes to protect her from the sun. She does not go outside for physical education, the window shades in her classrooms are always pulled down, she rides to and from school in a bus with tinted windows and is the last child picked up in the morning and the first dropped off in the evening, to minimize her exposure time even through the windows. Elaine also told the other meeting attendees about the SunGuard powder (made by RIT) that she uses to treat Elizabeth's clothes so that she can buy the same clothes all her friends are wearing and have sun protection added to them.

Elaine and her family held the meeting at their local church in Council Bluffs, IA. Some church members attended to show their support and learn about the family's struggles with porphyria. Elaine also saved some of the APF literature for the parish nurses, who were unable to attend. These are nurses in the congregation who have undergone additional training that enables them to care for children in the congregation who have health issues. Now they will have a head start on giving immediate attention to congregants with porphyria, as well. Finally, Elaine and her family showed the APF educational DVD. It was a wonderful day for all.

**Think of the APF when you receive your tax refund check. You can put that money to work training new porphyria specialists in the *Protect the Future* campaign. New porphyria specialists are desperately needed.**

## The Sum of Our Days

by Isabel Allende



World-renowned author Isabel Allende begins her new memoir with the scattering of her daughter Paula's ashes in the woods near her California home. Paula died young, after spending a year in a coma brought on by an acute porphyria attack. *Paula* (1994), a best seller, was Allende's account of her family's history, begun as a letter to her daughter in the hope that Paula would be able to read and understand her own history once she recovered from her illness. *The Sum of Our Days* picks up where *Paula* left off. Allende again writes to her daughter, recounting the events in the family's life since Paula's death, reconstructed from the author's daily letters to her mother in Chile.



USA Today calls *Paula* "one of the most moving books ever written about grief." With publication of *The Sum of Our Days*, Allende again honors her daughter's memory in a spirit to which anybody who has lost a loved one can relate. *The Sum of Our Days* is Allende's 17th book. Some of her others are:



The Infinite Plan



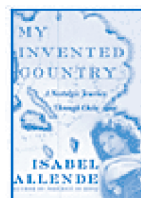
The Stories of Eva Luna



Aphrodite



Daughter of Fortune



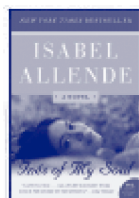
My Invented Country



Zorro



Forest of the Pygmies



Inés of My Soul



The House of the Spirits



La Gorda de Porcelana



Of Love and Shadows



Eva Luna

## In Memory

We are most grateful that the following individuals have made donations to the APF in memory of their loved ones: Floyd D. Firchow, Barbara and Richard Blumberg, Rick Burger, Joe Tacker, Eileen Hartley, Cathy Brazil, Penelope Dunham for **Gene Bennett**.

Katrina Spaunhurst, Bonnie and Gil Ford, Kathleen Toelkes, Jean and Anthony Pagano, Christa Friedrich, Shirley Ford, Helen Evers, Ardell E. Fromm for **Donna Pagano**.

Catherine Steinmann, Jennifer and Peter C. Gyr, Robert Olden, Eileen and Martin Regan, Mary Anne Loftus, The Peter Stuyvesant Little League, Connie Milillo for **Sharon "Peach" Staszyn**.

Barbara and Peter MacKinnon, Theresa and Frank Coleman, Linda M. Vredenburgh, Sally and Robert Young, James E. Arzouman, The John MacKinnon Family, Tery Schooler for **Susan Arzouman**.

And,

Dolores M. Brazas for **Wesley J. Brazas**, Daniel P. O'Toole for **Emilia O'Toole** and **Donna Pagano**, Grace and Frank Feczko for **Robert Zieles**, Mary D. McNitt for **Vivian Busse**, Charlotte Beck for **Elva de ne Guerre**, Geraldine Williams for **Birtie Prine**, Jack L. Mayfield for **Bettye Mayfield**, Diane L. Levere for **Dr. Richard D. Levere**, Diane and George Paquet for **Helen Karjanski**, Mary C. Brady for **Geraldine Busse**, Lois Beishir for **Sylvia Gates**, Ann and Stephen Hallberg for **Patricia Depukat**.

Thank you for honoring their memory is such a thoughtful way.

## In Honor

The following people were honored by their family and friends by a gift to the APF: Robert P. Quigley for **Dr. Peter V. Tishler**, Gary E. Eyster for **Ralph Gray**, Gunnar Lovblom for **Ralph Gray**, Lois Beishir for **Sylvester Beishir, III**, Carol A. Hughes for **Susan Young**.



Many of you have been touched by our office administrator, **Yvette Strange**, and might want to express your condolences over the loss of her mother. Her mother, **Margaretha Morand**, passed away unexpectedly Sunday, May 11. For almost 15 years, Margaretha was a dear friend to all of us. She helped the APF staff on many of our projects, including the newsletters. Long before we could afford an automated system, Margaretha kindly helped us sort the newsletters for bulk mail and ready it to mail to each of you. She also assisted us with other major projects when we were far too overloaded to finish them on time.

We will miss her very much and send our sincerest sympathy to Yvette. If you would like to send Yvette your condolences, you can contact her at the APF address: 4900 Woodway #780, Houston, TX 77056.



## Clinuvel Enters final phase clinical trial

A drug that could give a suntan via injection is a step closer to hitting the market after European authorities granted it a special status to speed up its development. The drug, CUV1647, manufactured by Clinuvel Pharmaceuticals a German-Australian company, is due to undergo a phase-three clinical trial next year for treatment of the disorders erythropoietic protoporphyria (EPP) and congenital erythropoietic porphyria (CEP). This will be the final regulatory hurdle before it can be sold in Europe. So far, the drug has passed its testing phases without significant safety concerns.

CUV1647 is an injection that stimulates the production of melanin in the skin. This protects against UV radiation by giving the skin color for 60 days after treatment. The drug has been given the European "orphan medicinal product" designation which is similar to the orphan drug status in the US.

CUV1647 may appeal to drug developers worldwide as a cosmetic product. It darkens the skin, giving it a tanned look without sun exposure. It also has possible uses in the treatment of skin cancer. Dr. Elisabeth Minder gave an excellent presentation on CUV1647 at the APF patient and expert meeting in Houston in October of last year.

For more information on volunteering for the trial, have a look at: <http://clinicaltrials.gov/ct2/results?term=cuv1647>.

## Late-onset EPP case in England

Doctors in Britain have reported a case in which a woman began to have symptoms of EPP at age 44. (Symptoms of EPP usually appear in infancy.) After the first week of her summer vacation in Spain and Portugal, the patient began to feel the intense itching of EPP on the sun-exposed areas of her skin. The itching was severe enough to keep her awake at night. The diagnosis of EPP was confirmed by DNA and the woman's sister was tested as well. The sister had the same mutation but was asymptomatic.

As reported in: L. Berroeta, et al, "Late presentation of erythropoietic protoporphyria: case report and genetic analysis of family members," *British Journal of Dermatology* 2007 157, pp1030-1031.

**Camp Sundown was founded for sun sensitive children. In New York State, the camp provides photosensitive kids with the outdoor fun of summer camp on a schedule that protects their skin from sun damage. For more information, see the camp's website: <http://www.xps.org/campsundown.htm>**

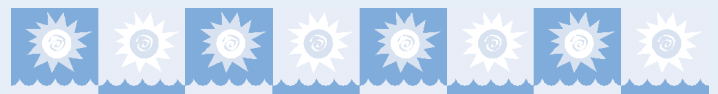
## Do you have CEP?

If so, chances are you have never met anyone else like you. The APF would like to change that. We want our members with Congenital Erythropoietic Porphyria (CEP) and their families to meet one another to share experiences and support.

CEP, also known as Gunther's Disease, is extremely rare with less than 200 documented cases worldwide. Symptoms usually begin in infancy, although the disease can cause anemia even before birth, and in less severe cases symptoms can develop in adulthood. Skin photosensitivity is extreme in CEP, causing blistering, scarring, excessive hair growth and thickening of the skin. Cumulative blistering and scarring is sometimes severe enough that the extremities — fingers and/or facial features — can be disfigured or lost through skin damage and infection. Although heme production is either normal or increased in CEP, patients often require blood transfusions because the disease shortens the life span of red blood cells.

Members diagnosed with the more common types of porphyria have enjoyed the benefits of communicating with others who share their diagnosis through the IN TOUCH network. If you or your children have CEP and are interested in enjoying the fellowship and learning that comes from meeting others who understand the challenges you've faced, please write to the APF and let us know. Then watch our website and your ENEWS Updates for more information on how you can meet or communicate with other CEP families.

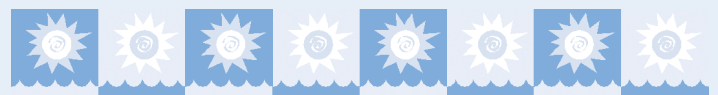
We would also like to have your story. Remember that many people have seen a story of a child or adult with one of the porphyrias and have emailed or called immediately to ask questions and learn more about their diagnosis. Your stories are powerful. Please send them to the APF or to [lyonapf@aol.com](mailto:lyonapf@aol.com).



### Summer's here: Time to protect your skin

*If you have a cutaneous form of porphyria, it's time to swing into action again. Stock up on and use a high quality sunblock, get covered up with protective clothing, and enjoy.*

*If you do get sores or blisters, be sure to have them treated so you don't develop an infection. Let's make this a healthy season for all of us!*



## Your efforts helped save a life

Many thanks to those of you who wrote urging the Canadian government to allow Laila Suan Elumbra, who was desperately ill with acute porphyria, to remain in that country legally. Laila was recently granted permanent residency in Canada after struggling with Canadian immigration regulations and AIP for nearly two years.

Elumbra arrived in Canada from the Philippines in 2004 to work as a nanny under Canada's Live-In Caregiver program. This would have allowed her to apply for permanent residency at the end of two years' work. But in June of 2006, after 22 months of work, just two months short of the time required before she could apply for permanent residency, Laila became gravely ill. She was hospitalized and unable to continue with her job. She slipped into a coma that would last four months, and was diagnosed with AIP during her time in the hospital.

When Laila entered the hospital and stopped working, immigration officials issued a voluntary deportation order for her; they would later reject Elumbra's request for special consideration due to her illness.

Finally, Laila Suan Elumbra's case has a happy ending. Congratulations to all of you who spoke up with compassion and support for her. You have helped a very sick woman reach the goal for which she worked so hard. Today Elumbra is living a happy, normal life in Canada.

## Going strong in southern California

The southern California porphyria support group met on March 30 in Orange, California. We had a lovely enclosed garden room at Spiro's Restaurant almost entirely to ourselves. We were four patients, representing AIP, VP and EPP, and a few friends and family members. One of the AIP patients received her diagnosis more than 20 years ago and has considerable experience with medications and various portable catheters for IV therapy.

One of the primary topics of discussion was the difficulty of being treated by doctors who have a limited knowledge of diagnostic procedures, safe drug therapy for pain and the varying symptoms of porphyria. We also discussed a Porphyria awareness plan directed at the local medical community, specifically ER staff.

All in all, it was a Sunday afternoon well spent giving and receiving support. Many thanks to all who were able to attend!  
— **Doris Stephens**



## Our Outstretched Hand

As we send this issue of the newsletter out to you, THE AMERICAN PORPHYRIA FOUNDATION is hosting an educational meeting at the University of São Paulo, Brazil and the Albert Einstein Hospital, as part of our *Protect the Future* program. Dr Karl Anderson from

the University of Texas Medical Branch in Galveston will speak on the *Porphyrias: Clinical Features, Diagnosis and Treatment* and Dr. Robert Desnick of the Mt. Sinai Medical School in New York City will present on *Molecular Genetics and Diagnosis*.

Both meetings are extremely important in our efforts to promote porphyria education and awareness among physicians — not only in Brazil, but in all of South America. By working with our friends internationally, we are widening and deepening the resources of the next generation of porphyria doctors. Dr. Charles Lourenço, the *Protect the Future* physician from Brazil, has assisted us with the meetings, including organizing educational materials for the 400 attendees of the Genetics Congress in São Paulo.

Dr Richard Villarreal from Colombia will also be attending the presentation. He started a Porphyria Foundation, which is one of our Global Partners, after his wife was diagnosed with AIP.

We also sincerely appreciate the efforts of Dr. Eder Quintão, who facilitated our meeting at the University of São Paulo, assisted with the translation of Dr. Anderson's and Dr. Desnick's presentations and helped with the many preparations necessary for such an undertaking. We also sincerely appreciate the efforts of our Brazilian friends, Ieda and Benie Bussman, who arranged our meeting at the Albert Einstein Hospital in São Paulo. And, of course, we appreciate Dr. Karl Anderson and Dr Robert Desnick, for their hands of friendship.

**The Future is Yours**  
**The APF and our Scientific Advisory Board are working to protect your and your children's future by training a new generation of porphyria doctors. Please help by making a gift to the Protect the Future campaign. Ask your employer about possible gift-matching too. All donations are tax-deductible.**



*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.*

*All information and content on this Web site are protected by copyright. All rights are reserved. Users are prohibited from modifying, copying, distributing, transmitting, displaying, publishing, selling, licensing, creating derivative works, or using any information available on or through the site for commercial or public purposes.*

*Also, the APF makes available to the public the Tax forms 990. For a copy contact the APF toll free 866 APF 3635.*

## What's New on the APF Web Site [www.porphyrifoundation.com](http://www.porphyrifoundation.com)

**Acute Porphyria Drug Database** Many of you participated in the drug study with Dr. Peter Tishler. Members can still participate by informing us of their reaction to a new drug: good or bad. Please let us know for future research. The resulting safe and unsafe drug list appears on the website home page.

AND ... We also now have the APF contact information and Drug Safety address on a calling card. We will include the cards with new member packets, in the ER kits and for those who send a stamped addressed envelope.

**Global Partners** The APF has added Colombia, South America to our list of *Global Partners*. If you live in Colombia and need help, please see the website *Global Partners* section.

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

AMERICAN PORPHYRIA FOUNDATION  
4900 Woodway, Suite 780, Houston, TX 77056  
Address service requested

