



## SOUTHERN CALIFORNIA IN TOUCH MEETING

Recently, The Southern California Porphyria Support group was graciously hosted by **Mira Geffner** and her husband, **Paul Southworth** in their lovely home in Los Angeles.

We began the meeting with introductions and a little background. It very quickly became apparent we shared a common bond, including that we had been misunderstood by medical professionals who were not knowledgeable about porphyria. All of us agreed that the need of a local porphyria specialist was critical.

We shared a great deal of supportive information, including the need for an updated Safe/Unsafe drug list and learned that Dr. Peter Tishler (Harvard) was compiling an updated list supported by a grant from the APF. Our hostess then told us the APF had arranged for renowned specialist, Dr. Neville Pimstone, to participate in a conference call with a question and answer session.

Dr. Pimstone hails from South Africa where VP is the most prevalent genetic disease. Among his many impressive accomplishments, he has treated over 4000 Porphyria patients. He currently works at University of California Davis in Sacramento, where he was the head of the Liver Department, but he will be relocating to the LA area to be near his children and grandchildren. Working together with the APF, he hopes to establish a Porphyria Center in one of the teaching hospitals in Los Angeles to help educate doctors about porphyria and secure a place where patients can be diagnosed and treated.

The attendees included a wide range of ages and types of porphyria, which made the question and answer session with Dr. Pimstone quite varied and thus, more informative. Each person was afforded a generous amount of time to ask questions, and Dr. Pimstone graciously spent hours answering every question.

One attendee was a very ill young woman, who had numerous hospitalizations and was in a wheelchair. Her family had previously been in contact with Dr. Pimstone, and she had tentatively been diagnosed with an acute Porphyria but was still going through the trial and error of testing. Dr. Pimstone warned against anyone attempting to induce an attack or abstaining from necessary medications in order to possibly test positive for porphyria. The risk of permanent damage or even death is not worth it. Instead he suggested that people could freeze their specimens in attack if they were not able to travel to a hospital.

Aside from the many medical questions, one question was related to the variegate porphyria prevalent in South Africa.

Dr. Pimstone delighted in giving a little history of the origination of the disease. In 1688, forty Dutchman migrated from Holland to grow crops and feed the troops stationed in South Africa. The gene trait was traced back to one orphan girl from this group who had 11 children with various fathers during this time. Interestingly, all of the children inherited VP. Today, VP is quite widespread among the Dutch population, who are known as Afrikaners.

Dr. Pimstone also encouraged us to support the APF efforts to have a porphyria center in this area. I spoke with Desiree at the APF, and they would appreciate it if members would write a letter (not an email) to the APF, stating their need for establishing a Porphyria Center in Los Angeles. Given enough interest, it just might happen! **Doris Stephens**

*Editors note: Please read Doris' very interesting story in the Member Story section of our website. Also, Mira's account of the meeting can be read on the APF website.*

## The In Touch Network and You

The APF IN TOUCH network is not just a means for people with porphyria to meet and greet one another but it is also a very important educational avenue. When an IN TOUCH meeting is organized, the APF will announce the meeting on the website, as well as send a notice to all of the members in your area and facilitate a conference call with a porphyria specialist like Dr. Pimstone.

One of the upcoming meetings will be hosted by **Patsy Brady on October 7, 2006**. Several other meetings are scheduled, including meetings in Houston and Atlanta. Please check the APF website for information and directions: [www.porphyrifoundation.com](http://www.porphyrifoundation.com).

**WE NEED  
YOU**  
**TO HOST AN IN TOUCH MEETING**  
**CONTACT LELIA BROUGHER:**  
**[email@brougthers.com](mailto:email@brougthers.com)**



## Lyon's Share: A Chance For the Future

Thirty plus years ago as a newly diagnosed twenty-eight year old, I became a patient on the metabolic ward of the research hospital at The National Institutes of Health (NIH). At that time, porphyria experts diagnosed and treated patients there. The porphyria program closed when the head, Dr. Donald Tschudy, retired.

**Dr. Herbert Bonkovsky**

Fortunately, Dr. Tschudy's protégés are still treating us. However, the porphyria section of the NIH closed,

leaving the patients there with no porphyria expert. Not knowing where to turn, I went to the major medical journals and textbooks to see who had written the articles on porphyria. I knew to be selected to write an article in those prestigious publications, the doctor/author had to be recognized as an expert on the subject by his peers.

I repeatedly noticed the name of one doctor at Rockefeller Hospital in New York City and promptly called for an appointment. I became a patient there and with the excellent care I received, I improved rapidly. However, a few years later, that porphyria program closed, too. I was fortunate to relocate near the same expert and continue my outstanding medical care. But not everyone has the opportunity to live near a specialist. But location is not the only problem, rather, the number of experts has diminished. We need to train new experts as soon as possible. Unless we prepare for the future, we truly run the risk of losing the present expertise.

Dr. Gagen Sood was the first doctor selected for our **Protecting Our Future** campaign, but we need more than one. Now porphyria expert, **Dr. Herbert Bonkovsky** (in photo) at the University of Connecticut, has located an outstanding candidate for the training program. But the APF cannot support another trainee doctor without your help.

We understand that you are pulled many ways for donations and all of these needs are great. However, to have an expert the caliber of **Dr. Bonkovsky** train a young physician is an extraordinary opportunity. I personally, will be making a contribution to the **Protecting Our Future** appeal. Government funds for rare diseases are almost nonexistent, so we really must take advantage of this opportunity. Our lives depend on it.

Please join me in contributing to this appeal. If you are writing a check, please note that it is for **Protecting Our Future**.  
**Desiree Lyon**



## Media Attention to Porphyria

The last month has been a media boom for porphyria. First, the article on rare disorders in *Parade* magazine, included a good piece on porphyria. Next, ABC's *Primetime Live: Medical Mysteries* aired a show about one of our members, Casey Knauff of Bellefonte, PA. Casey is a 5 year old girl who suffers from Congenital Erythropoietic Porphyria (CEP), which is the rarest and most difficult form of porphyria. CNN filmed a story on the Knauffs earlier this year.

Also, *Mystery ER*, a popular program on the Discovery Health Channel, will air a segment on one of our members who has AIP. We have discovered that the amount of media attention we have received has been in direct relation to our APF media awareness campaign.

*We hope all of you saw these programs. If not, you should send the APF your email, so we can place you on the E-News list. If you receive the APF internet E-News, you can be advised on air times for upcoming programs, as well as other important notices.*

## Protoporphyrin Tests: Make Sure They Are Correct

It is important for people with EPP to have proper testing performed. They should have their protoporphyrin levels checked at least once a year. Sometimes plasma porphyrins or zinc protoporphyrin levels are measured but are not appropriate for EPP. Instead, red blood cell (RBC) porphyrin levels need to be determined. Erythrocyte is the scientific term for RBCs.

EPP test involve porphyrins, fractionation, RBC tests, the fractionation and RBC, both of which measure protoporphyrins. The porphyrin fractionation test measures the different kinds of porphyrins present in the RBCs as well as the protoporphyrin. Usually, however, there are no others than the protoporphyrin. The total porphyrin test merely measures all present in a lump sum, as there is usually only protoporphyrin present, the figure represents the amount of protoporphyrin present.

Your doctor may want to know that the tests can be performed at the Porphyria Lab in Galveston, Texas or the Mayo Labs in Rochester, Minnesota.

*We thank the EPP Research and Education Foundation EPPREF for sharing this information.*

**Watch for news on a new NYC Center**



## And Then There Was Light Cheryl Black-Blair

To say my life was nothing but darkness would be going too far and denying my Christian faith, but there were times when I felt I could not go on. The pain from Acute Intermittent Porphyruria (AIP) was wracking my body so completely that I would go without sleep for days. It was affecting me emotionally

as well. There were days when I'd call friends and prayer partners in desperation, because I felt like ending it all. Like many of you, my AIP went undiagnosed for years. The doctors were convinced it was menstrual pain and put me on high-dose birth control pills. The pain only worsened. My urine turned the color of Merlot wine, so the doctors tested it, found no sign of blood and then dismissed it. The attacks continued with a seemingly endless series of examinations and doctors, but fortunately I never had exploratory surgery. When I was finally diagnosed, the doctor returned in tears knowing how many years I'd suffered without hope or treatment.

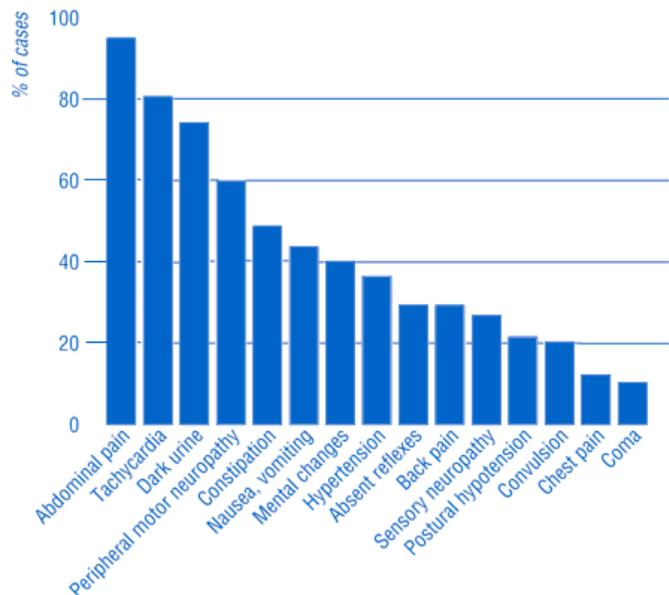
Why was I suffering with attacks twelve years after diagnosis? I'd been hospitalized frequently and given the usual glucose IV along with Demerol for the pain but the relief would not last. Some days were better than others, but the trend was always downward and I was spending much of my life in bed. I'd started having seizures a few weeks prior, and my new doctor put me on anti-seizure medication after verifying its safety on the American Porphyria Foundation's website. This doctor was special and was instrumental in what happened next after my pain worsened, and I lost control of my bladder and other muscles. A friend then called with information on Panhematin® treatment as the first response for someone in an attack. He sent the article and a "Panhematin® Treatment" page from the APF website. The doctor ordered the Panhematin® and I began the treatment the next day. What a difference in results compared to my glucose treatments. After the treatment, I fell asleep for the first time in days. After my second treatment, I had my first revelation: I could think again!

Going into this attack had been like driving into mist that slowly changed into dense fog; surrounded in a gray depression where I struggled with even simple tasks. Suddenly, I woke up in the light! The fog had vanished, and along with it the hopelessness. When my friend called, he said, "Just listen to yourself – you're not stuttering anymore. This is incredible. You are finally back again. Thank God!" It was then I knew that many prayers for healing had been answered. By morning, most of the pain in my abdomen had disappeared and the bloating was down noticeably. Even better: the awful pain throughout my body was easing and the rest of the symptoms eased over the course of the treatment. When I called the APF to thank them for all they've done for me, they told me something totally unexpected.

Apparently, many people with porphyria are reluctant to have Panhematin® treatment, which to me is overestimating the risks while underestimating the benefits. It is for those of you who suffer without hope as I did that I am writing this article. I urge you to have your doctor call the APF to find out more about porphyria and Panhematin®.

## Frequency of Symptoms

Many of you have asked about the classic symptoms of the acute porphyrias. The scale below was published in the *British Medical Journal*. How do you compare?



## Family Tree DNA

Family Tree DNA is America's first and world leader in genealogy driven testing service. They have been constantly developing the science that enables many genealogists around the world to advance their families' research. Family Tree DNA provides the tests for the partnership between the National Geographic Society, IBM, etc.

If you want to be tested, you will receive specific data about yourself and a series of other relevant information, like deep ancestral origins, matches with other individuals that share the same results, your recent ethnic origins, and for the Y-DNA, the Predictor to the Most Recent Common Ancestor between you and other individuals that are relevant matches to you.

This is **NOT A TEST for porphyria** and will not show any medically related information. You might, however, find a distant relative that you didn't know who has porphyria through this fun exercise. For information, go to [www.familytreedna.com](http://www.familytreedna.com) or call 713-868-1438.



## I have had Acute Intermittent Porphyria

since I was eighteen. I am now twenty-five years old, so my family and I have been dealing with porphyria for seven long years. Porphyria causes excruciating pain in my chest, bones, muscles, and stomach, which is the most excruciating pain anyone could possibly imagine. I was hospitalized and on morphine for almost a month until I was diagnosed even though my mother had AIP. Since she is from Columbia, it took several confrontations before a doctor would pay attention to her and test for porphyria. Once diagnosed, the doctor treated me with Panhematin, glucose and morphine, which worked like a miracle in only three days.

At the beginning of my diagnosis, I had attacks every few months and was admitted to the hospital. Now, however, my attacks are more frequent and more dangerous. Now I am in and out of the hospital every month with attacks and complications like seizures,

neuropathy and punctured lungs. I even lost so much weight that I had to have a feeding tube that has helped considerably. In my search for a cure, I went to the University of Texas Medical Branch where I volunteered for a research project and also met my dear friend, Mary Adamchick. Mary had AIP attacks monthly. Sadly, after returning home she had an attack and died. I send my love to her husband Alan and their baby boy.

When I was first diagnosed, I found out about the APF from a very good friend of mine named Peter. He was so worried about me that he researched my newly diagnosed disorder. At first I did not want to read about my disorder. At that time, I was mad at God but now He has showed me that I am not alone. He has saved me from dying many times and given me a mother and a husband, (see photo) who never leave my side when I am sick. I have a wonderful family who loves and supports me. Also, the APF has helped me contact with a network of people with porphyria. The IN TOUCH meetings help us all gain a better understanding of porphyria as well as hope. *Thank you Lord for giving me my family, my health, and most important, for giving me Your love and letting me know that with You by my side I need nothing more. Your friend, Jennifer Gattoni*

## International Requests

Recently, a Filipino woman, who was working as a nanny in Montreal, was ordered to leave the country under unusual circumstances. She fell into a coma and remained in the coma for four months. She unknowingly had acute porphyria and was critically ill and has been recovering ever since. At the time of her illness, she was working as a nanny. Her lengthy coma kept her unable to work two months short of the work requirement for immigrants. Now immigration officials are moving to have her deported because they say she is two months short of fulfilling her work requirements under the Live In Caregiver Program. If she'd completed the extra days, she would've been eligible to apply for permanent residency. The APF is helping her return to work and hopefully, remain in Canada.

In another instance, we received the saddest request and photos ever from the family of a young girl in Columbia. She had CEP, the rarest and most damaging type of porphyria. The child had huge, raw sections of her flesh exposed and open on her face, hands and arms. In the photos we received, the dear little girl was standing in the sun, the most virulent place to be. I cried when I saw the photo and began to search for help. Even now, a month later, I am haunted about what to do for this child. We have a specialist who will consult with the doctor in Columbia, but transportation issues and other problems make it difficult to bring her here for treatment. My hope is that someone or some organization will reach out and assist us with this crisis.

Recently, too, the brother of a very sick man in India, called the APF for help in securing treatment and consultation with a specialist. As usual, members of our board of experts also volunteered to consult with the man's physician in India. Within days, the man had the help he needed. Once again, we rested in the knowledge that we all had been participants in a life saving measure.

This year we have received requests for help from around the world including: India, Mexico, Argentina, Ireland, Columbia, France, South Africa, Romania, Bolivia, Germany, Spain, England, Australia, South Korea, Phillipines, Canada, Switzerland, Indonesia, Malaysia, and Pakistan.

It is a gratifying experience to be able to provide assistance to people around the world. [Your gifts have made this possible.](#)

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## Dr. Neville Pimstone



Dr. Neville Pimstone serves on the APF Scientific Advisory Board. We thank him for his assistance at the recent Southern California IN TOUCH network meeting and for his many years of dedicated service to people with porphyria. Interestingly, Dr. Pimstone hails from South Africa where he developed his expertise with the acute porphyrias.

Among his many honors, Dr. Pimstone received the first "Physician of the Year" award ever bestowed in the Sacramento area by the Northern California Chapter of the American Liver Foundation. The foundation chose Dr. Pimstone for the honor in recognition of his academic, research and clinical contributions in the area of liver diseases. He has also been highly recognized for implementing aggressive clinical trials to test new medication and approaches for the treatment of Hepatitis C. We, of course, honor him for his research and service to porphyria patients.

Dr. Pimstone recently departed his position as professor of medicine and Chief of Hepatology and Gastroenterology at the UC Davis School of Medicine to live near his children and grandchildren in Los Angeles. In fact, we are working to establish a porphyria center in the Los Angeles area with

Dr. Pimstone as the expert in charge. The number of porphyria patients is quite large and yet there is no porphyria specialist to treat them or guide their primary care physicians. We hope to fill this need soon but are concerned about the void Dr. Pimstone's absence will create for our members near UC Davis.

## Use of Albumin With Panhematin?

We often receive questions regarding Panhematin and Albumin. We would like to hear your experience. Here is **Mira Geffner's**

**Answer:** When I first met Dr. Herbert Bonkovsky during my participation in the Porphozym study, I had a chance to ask him if I was alone in getting severe headaches, nausea and vomiting following heme-albumin infusions. I first experienced these side-effects after five years of frequent infusions and have had them with all of my infusions ever since. Dr. Bonkovsky explained that, although the exact reasons for the symptoms remain uncertain, he has observed them both in persons with acute porphyrias and in normal control persons. It seems likely that the headaches, and perhaps the nausea and vomiting, are caused chiefly by an increase in the volume of fluid in the blood stream and, thus, in the head. This increase in fluid volume is a known effect of albumin. Nevertheless, porphyria experts do recommend mixing Panhematin with albumin, because this helps stabilize the heme and reduces the risk of phlebitis, which is painful and damaging to veins.

At Dr. Bonkovsky's suggestion, I have slightly decreased the amount of water I drink daily while I am receiving infusions. I still get headaches, but they are much milder. More importantly, decreasing my fluid intake on treatment days has stopped the vomiting; I am recovering from attacks more quickly now because I am able to take in carbohydrates and calories during treatment. Interestingly, I know three other women who have received frequent Panhematin-albumin infusions, and all of them have experienced the headaches or nausea to some degree. Yet, not one has said she would forego treating an attack because of the side-effects. Some patients compromise by receiving Panhematin infusions via a Port-a-cath and skipping the albumin even though it can still lead to clots.

Having had attacks almost every month for the better part of 10 years, I still choose Panhematin with albumin over Panhematin alone. Not receiving Panhematin at all is not an option; my two most dangerous attacks were the ones I had before my doctors started treating me with heme. Even with heme-arginate, which is widely used throughout Europe, thromboses and phlebitis also occur. Most porphyria physicians in Europe now also administer heme-arginate in albumin.

Read: (**Important Treatment Up-date: April 4, 2006 Annals of Internal Medicine published a letter by Drs. Anderson, Bonkovsky, et al** (Reconstitution of Panhematin for Intravenous Infusion. vol. 144, issue 7: pp. 537-8).)

*Thanks to Dr. Herbert Bonkovsky for his generous contributions to this article and to Rose Jeans for editing.*

## Liquid Beta-Carotene

One EPP dad found a Compounding Pharmacy which was able to mix the beta-carotene with flavored syrup to make it easy for children to take the recommended two capsules of beta-carotene. By using the Hoffman LaRoche beadlets, he mixed them with sugar and then as the child takes each dose, it is mixed into a syrupy mixture which dissolves the beadlets.

Since the pharmacist makes the capsules at the pharmacy, and uses the prescription grade beta-carotene, he was able to submit the bill to the insurance company and receive payment. The same insurance company would not approve payment for *Lumitene*, the high pharmaceutical grade beta-carotene recommended for EPP. If you would like further information, contact the APF.

*We thank the EPP Research and Education Foundation EPPREF for sharing this information.*



## IN MEMORY

We want to extend our deepest sympathy to several families who have recently lost their loved ones. Mary Adamshick passed away after courageously battling AIP and the devastating pain for nine years. She was grateful to the APF for their support and inspiration. Her husband, Alan, expressed his appreciation to Dr. Herbert Bonkovsky for the wonderful care he provided Mary. Sadly, Mrs. Madeline Marston lost her husband James Vincent Marston. Ms. Cecily Carlvert lost her mother Martha Meads Tooley, who was diagnosed only a few years ago. Cecily commented that porphyria is difficult when you don't have a knowledgeable doctor. Each of these families asked that memorial donations be sent to the APF educational and research projects.

We thank the many families who have honored the memory of their friends through their donations.

Mr. and Mrs. Bruce Greenwood, Betsy Roberts, Sarah MacDonald, Nancy and Bill Richert, Carolyn Kruger, Heidi Beckwith, Marie and Bernard Weiss, Fedora and Frank Stenger, Marilyn and Arthur Ickes, and Virginia and Paul Wenzel for Mark Greenwood. Joanne and Vincent Kane, Terry Housley, Thomas Bitz, and Friends at Beacon Converters, Inc, for Mary Adamshick, and William S. Bell for John T Landon, and Elaine Smuczynski for Helen Smuczynski, and Gertrude and Howard Stephens, Mayetta Dees and Family for Lawrence Alvie Reynolds and Susan and Anthony Stocker, Dorothy and George H. Burke, Susan M. Conover, Mary C. Lickfeld, Joan and Earl Thatcher, Herbert D. Kling, Theodora A. Nieder, Joan and Robert Russell, and The Runnemedede Senior Citizens Club for James Marston, Ann L. Hallberg for Patricia Depukat, Barbara and Joseph Cragan and Fredric and Beth Sponholtz for Clara Zaremba and Margaret and Patrick Harkness for Polly Cutler and Gloria Sheehan for Paul Sheehan and Donna L. Pagano for Arlene Yager and Donna L. Pagano for Millie O'Toole.

Also, many of our members have been honored with the donations of their good friends and family members. George R. Nielsen for George Hanson and Cletus P. Hawtin and Rosalie Nielsen for Lisa Kancsar.



## From the Desk of Yvette:

Many of our members may be curious to know what a typical day at the office is like. Our work is multifaceted but our main objective is to provide information and direction to the many people who reach out to us for help. This includes providing references to porphyria specialists for diagnosis and treatment.

Our APF work also includes answering the many phone calls and emails that pour in daily form around the globe. Interestingly, APF members, newly diagnosed patients, their families, friends, doctors, and

even the media contact us with innumerable multifaceted questions, requests, and needs. But sometimes, we are here to just be good listeners to patients who are often bewildered and frustrated with their disease. At times, a patient's situation is so complex that we ask Desiree to step in to help find the proper recommendation to their situation.

Since information about porphyria is not always easy to find or understand, we all serve as guides and teachers. When people with porphyria find our foundation, they are so grateful. They

often comment on our superb website and educational materials. Since the APF membership has grown so much over the past decade, our mail, requests for assistance and record keeping have increased exponentially. My job mainly centers on overseeing our memberships and the financial responsibilities, including facilitating the transfer of donations to each respective grant. The need and demand of our **IN TOUCH** network has also greatly increased. The **IN TOUCH** list we provide each member has proven to be a vital part of our services. This is just a caption of our busy but gratifying days. Everyone who works with the APF is committed to our members and their need for the best information and assistance possible.

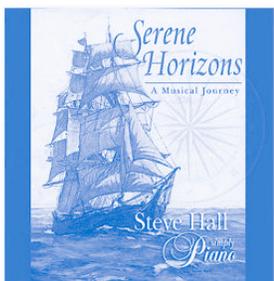
## Measuring Light for EPP

In response to many questions about measuring light rays that trigger EPP, Dr. Michelene Mathews Roth, asked the question of an optical instrument company. She discovered that an ordinary photographic light meter fitted with a blue photographic filter that transmits light from 360 to 480 nanometers, the wave length that triggers EPP reactions. Such a filter is the Kodak Wratten Filter, number 47, Blue Tricolor, 3 inches square, Kodak catalogue number 1495787.

This filter is made of gelatin, so it is a good idea to put it between two pieces of glass to preserve it. Window glass transmits light from 340 nanometers and above, so the important wavelengths will go through it.

We thank the EPP Research and Education Foundation EPPREF for sharing this information.

## What One Woman Can Do



**APF member, Jennie Eberhardt**, has been awarded the 2006 APF Ambassador for the work she has done in her community. She is a one-woman porphyria awareness dynamo. Before her illness, Jennie enjoyed a successful career as a professional make-up artist with theaters and photographers. Her work took on other unusual aspects. For instance, she created mock victims to help train ambulance crews for disaster drills. She also did the make-up for cancer patients. One of her most gratifying experiences was to create a jaw line for a woman who had lost part of her jaw to throat cancer surgery. But her most enjoyable career experience was as the make-up artist for a production with female impersonators. In fact, Jennie developed such a great relationship with her clients that they are now some of her biggest supporters and encouragers since her illness.

Jennie's career also encompassed beauty pageants and image consulting; an active life to be suddenly halted when she developed severe chemical sensitivities. Then she was also diagnosed with AIP. But Jennie "made lemonade" out of her mound of lemons by changing from a career of sales and marketing to a "ministry" of promoting porphyria awareness and education. As a very active member of the IN TOUCH network, Jennie has provided a loving shoulder for many of our APF members.

Now Jennie is also involved in a special fund raising effort. One of her friends, international Steinway concert pianist, **Steve Hall, has offered to perform for an APF concert at 3:00pm on October 1, 2006 in Racine, Wisconsin at the St. Andrews Lutheran Church, 1015 Four Mile Road.** Her many friends, neighbors and business associates have joined in the effort by donating their time, as well as door prizes, printing etc. Jennie and her husband, Rich, their two daughters and five grandchildren invite you to help with the event and then join them at the concert. Please contact Jennie at [porphyriawi@aol.com](mailto:porphyriawi@aol.com).

### Fentanyl and You

We have received a number of questions regarding Fentanyl. Medline information is that fentanyl (FEN-ta-nil) belongs to the group of medicines called narcotic analgesics, which are used to relieve pain. According to the *New York Times*, The FDA is investigating 120 deaths tied to the Duragesic® pain patches made by Johnson & Johnson and Mylan Laboratories. The patches, introduced in 1990, release the opiate fentanyl through the skin. Fentanyl also is prescribed as Actiq®, a transmucosal form of the drug.

The package inserts are very informative. One important fact appears in the insert: **"DURAGESIC® should ONLY be used in patients who are already receiving opioid therapy, who have demonstrated opioid tolerance, and who require a total daily dose at least equivalent to DURAGESIC® 25 mcg/ht."** It also says, **"DURAGESIC® patches are intended for transdermal use (on intact skin) only. Using damaged or cut DURAGESIC® patches can lead to the rapid release of the contents of the DURAGESIC® patch and absorption of a potentially fatal dose of fentanyl."**

The Actiq® information sheet also says that, **"Transmucosal fentanyl is only used in patients who are already taking narcotic analgesics."** The inserts add, **"Patients who are considered opioid-tolerant are those who have been taking, for a week or longer, at least 60 mg of morphine daily, or at least 30 mg of oral oxycodone daily, or at least 8 mg of oral hydromorphone daily or an equianalgesic dose of another opioid."**

You may want to discuss these issues with your doctor if you are taking fentanyl.

### Physician Education: Virtual Web Teleconsultation Session

Recently, doctors were able to participate in a 30-minute **Virtual Web Teleconsultation Session on Recent Advances in Preventative Treatment Options for Acute Porphyrias and Current Concepts in the Treatment of Acute Porphyric Attacks.** The teleconference provided this multi-disciplinary group of physicians the opportunity to offer their expert insight and recommendations concerning two educational slide kit modules. The first module focused on current concepts in the treatment of acute porphyric attacks, and the second module focused on recent advances in preventative treatment options for acute porphyrias.

Porphyria Specialist, Dr. Joseph Bloomer, Professor of Medicine and Director of the Liver Center at the University of Alabama at Birmingham and APF Scientific Advisory Board member, conducted the web teleconference, which consisted of a 30-minute educational review of both slide kit modules followed by a brief 15-minute question and answer session and educational module assessment questionnaire. There were three teleconferences from which to choose so that any doctor who wanted to participate had a choice and did not have to meet this important educational opportunity.



AMERICAN PORPHYRIA FOUNDATION

*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 on the APF Web Site [www.porphyrifoundation.com](http://www.porphyrifoundation.com)

### International Porphyria Patient Conference

It is not too late to register and attend the International Porphyria Patient Conference in Rome on October 26 and 27. Join your fellow APF members for two enjoyable days with porphyria patients from around the world. See the website for details.

### Upcoming IN TOUCH meeting

There are three upcoming IN TOUCH meetings as follows: New York, Atlanta and Houston. Check out the dates, times and directions on the website. We need you to host a meeting in your area. If you are interested in participating, please contact: Lelia Brougher 404-550-4880.

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