AMERICAN PORPHYRIA FOUNDATION

2nd Quarter, 2007

## 2007 President's Award

**CONGRATULATIONS!!!** We are proud to announce that APF member, **Dave McRae**, has been presented with the **APF 2007 President's Award**. Dave and his wife, Laurie, are blessed with a wonderful family: Rebecca and Jake and three grandchildren, David, Alena and Alyssa.

Dave was diagnosed with EPP at age two and lived in sunny Southern California until he married and moved to Seattle for a better climate. Already a pro-active person, Dave added the APF to his list of helpful endeavors. He and Laurie hosted one of the first IN TOUCH meetings and from then on began enhancing awareness of porphyria in his community. A few years ago his doctor suggested that he should apply for handicapped parking privilege because of his EPP. He discovered that although some states allow parking passes for EPP under the "other" category, Washington only allows this privilege for mobility issues. Since there were no exceptions, he contacted his local state representative and together they drafted new legislation to allow handicapped parking privileges for light sensitive porphyrias. The bill made its way through a lengthy process and was **finally passed** in April to be effective 7-22-07.

Dave also serves on the APF government and advisory committees and has been instrumental in teaching other members how to accomplish important legislative health changes in their state. If you want to do the same in your state, please contact him at: **prendez.mccrae@comcast.net**

## Megan Lowry

We knew something was wrong with Megan soon after she was born. After placing her under the warming lights, she cried a great deal and became a burnt red color. At the time, we thought she had an allergic reaction to foods and did not make the connection to the sun even though she screamed when we took her outside. She, however, understood innately that the sun HURT, she didn't want to go outside. Eventually, she wanted to try again.

The result was horrendous. Her skin and lips swelled terribly and began to bleed. It was then we realized that the sun was causing her problems. The doctor said she may grow out of it, but she got worse. We demanded a second opinion and were subsequently given an appointment with a dermatologist six months hence. Before the appointment occurred, we had three inches of snow, so we covered Megan very well, lathered on sun screen and let her play in the snow. After fifteen minutes, she was severely burned and was rushed to the Children's Hospital where she was misdiagnosed again. Finally, we saw the dermatologist who after many incorrectly performed tests, diagnosed EPP and prescribed Lumitene, the high pharmaceutical grade beta carotene treatment for EPP.

We were asked to keep a log of her time in the sun. Through this record, we discovered that Megan could spend three and a half hours of sun time spread over seven days without making her sick. We also found that Megan had extreme severe photophobia (photosensitivity to the eyes), so they swelled badly as well.

One of her needs was a HANDICAP PARKING STICKER!! We called the county clerk and described Megan's plight. They mailed me the form and stamped on top of the form **Photosensitive Child-approval upon doctor's signature**. The doctor signed the form for us, so it was a simple matter. For others, acquiring the handicapped pass has been difficult. The sticker has been extremely helpful to Megan and to those who are very sun sensitive. We have also found a gym with dark windows and an indoor pool. Now Megan is having fun and leading a more normal life. And we park near, close to the door of our destination. This has been a great help!! Sarah Lowry

*Editor's note: We understand that some people feel these passes should only be given for a mobility handicap. Photosensitivity can be very severe, so a parking pass is essential in these cases.*

**VERY IMPORTANT**

**MORE TREATING PHYSICIANS FOR OUR MEMBERS:**
**THE APF HAS ADDED TO OUR LIST OF PHYSICIANS WHO TREAT PORPHYRIA. IF YOU NEED A DOCTOR IN YOUR AREA, PLEASE CONTACT THE APF.**

## EPP Testing

At times, some EPP people have the wrong tests performed. It is important for EPP people to keep an eye on their blood protoporphyrin levels, by having them tested on the average once a year, or more often if your doctor thinks it is needed. It is essential to have the proper test performed. The problem is that if someone asks for a free protoporphyrin measurement, it's not always clear what is measured. Therefore, it may be best to ask for a total erythrocyte protoporphyrin measurement. Then one can be sure what is being reported.

If that is normal, EPP is ruled out. If it is high, then the sample needs to be further tested to see if it is mostly free or zinc protoporphyrin.

The Porphyria Center Laboratory at the University of Texas in Galveston, can perform these important EPP tests. For more information, contact the APF, who will then place you in contact with EPP expert, Dr. Micheline Mathews-Roth, at Harvard. For collecting and shipping information, contact Dr. Hallberg at 1-409-772-4661.

## Measuring Light

EPP people have also asked if there was a way of measuring the amount of light rays that triggers EPP in daytime sun on any given day. EPP expert, Dr. Micheline Mathews-Roth, checked with an optical instrument company, and they suggested using an ordinary photographic light meter fitted with a blue photographic filter that transmits light from 360 to 480 nanometers, the triggering wavelengths for EPP reactions. Such a filter is the Kodak Wratten filter, number 47, Blue Tricolor, 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 about 340 nanometers and above, so the important wavelengths will penetrate. *Editor's note: We thank the EPPREF for allowing us to use this article.*

## Judy and Tom Phelps Host Ohio Meeting

Tom and Judy Phelps opened their home for an IN TOUCH meeting in Cincinnati, Ohio. Judy was diagnosed several years ago and has been an active advocate since that time. Tom, a physician, assists Judy in her awareness activities. Their recent IN TOUCH meeting was well attended with all ready to meet again soon.

## A Special Namesake

When new APF member, Shannon, was in terrible pain and needed a doctor, she called the APF for help. She was met with friendly voices: Elizabeth, Yvette and Desiree. Together they devised a plan to connect her with a specialist and the Emergency Room physician at her local hospital. Shannon surprised us by naming her new foal, Desiree, in honor of APF Executive Director, Desiree Lyon, who helped guide her through the complex diagnostic and treatment maze. Interestingly, the APF has had several very unusual members: *Cassidy* the Cat, *Alamo* the turtle, *Jup* the dog, *Orky* the lizard and now *Desiree* the foal. *Thanks, Shannon*

## Exciting News: Porphyria Center Opens in New York City

We are excited to announce that our long awaited Porphyria Center in New York City will be opening soon. In fact, it my be open by the distribution of this newsletter at the Mt Sinai Medical Center. **Dr. Manish Balwani** and **Dr. Lawrence Liu** will oversee the Center and will be the attending physicians. Through the APF ***Protect the Future*** training program, Drs. Balwani and Liu have become accomplished in the field of porphyria.

It has been almost two decades since NYC has had a center where porphyria patients could be diagnosed and treated. Since there are only a few centers in the country, this is a very special announcement. For information on how to make an appointment, contact: Toll Free 1-866-APF-3635.

We want to thank our APF members who helped in the training process by sharing their experiences with porphyria. Recently, **Birte Prine,** her daughter, **Geraldine Williams**, and several other APF members volunteered to assist Dr. Karl Anderson at the University of Texas Porphyria Center in Galveston with the training of several future porphyria experts. By sharing their experiences, they could help the trainees to more fully understand the often unusual symptoms of people who experience attacks, as well as discuss their treatment. These volunteers provided a learning experience that could never be gained in Medical Schools. With the help of our members, we can train more experts around the country through our ***Protect the Future*** program. Our APF goal is to open a center in three other cities as soon as possible. **Your financial support for the *Protect the Future* program is also needed to accomplish this most important life saving mission.**

# DNA Diagnosis for Porphyrias Now Available

The Porphyria DNA Testing Laboratory of the Department of Genetics and Genomic Sciences at the Mount Sinai School of Medicine in New York City is proud to announce availability of DNA testing for six porphyrias, including acute intermittent porphyria (AIP), hereditary coporporphyria (HCP), variegate porphyria (VP), familial porphyria cutanea tarda (f-PCT), erythropoietic protoporphyria (EPP) and congenital erythropoietc porphyria (CEP). We are the only laboratory in the United States to offer DNA testing for all of these porphyrias, and our testing program was developed with a grant from the American Porphyria Foundation. We thank the porphyria patients who sent us their blood to develop and validate these tests.

Before requesting DNA testing, we recommend that patients have biochemical testing (urinary, stool and/or plasma porphyrins and porphyrin precursors (ALA and PBG) and/or enzyme assays). However, many patients have not had an acute attack or are not symptomatic at present, so biochemical testing may be inconclusive.

In contrast, DNA testing is the most accurate and reliable method for determining if a person has a specific porphyria and is considered the "gold standard" for the diagnosis of genetic diseases. If a mutation (or change) in the DNA sequence is found in a specific porphyria-causing gene, the diagnosis of that porphyria is made. DNA analysis will detect more than 97% of known disease-causing mutations. DNA testing can be performed whether the patient is symptomatic or not and requires only a small amount of blood sent to our laboratory at room temperature. Family studies can then be performed to determine if relatives have inherited that porphyria, thus allowing identification of family members who should be counseled about appropriate management in order to avoid or minimize disease complications.

It is important for patients to realize the limitations of DNA testing. Each porphyria is caused by a mutation in the DNA sequence of a specific gene. Thus, the diagnosis of a specific porphyria determines the gene to test. Identifying the specific porphyria can be problematic as the three acute porphyrias (AIP, HCP, VP) typically have acute symptoms, biochemical findings, and responses to treatment. **For example, if a patient has been given the diagnosis of AIP and no AIP gene lesion is identified, it is possible that the patient has a different acute porphyria. For patients with symptoms of an acute porphyria, but without a specific diagnosis, we offer a "triple test" - which includes DNA testing for the three major acute porphyrias (AIP, HCP, and VP).**

DNA testing involves sophisticated DNA sequencing which is multi-procedural, labor intensive, and expensive. In the porphyrias, there are no common mutations and the entire gene must be sequenced in each new family. The cost for DNA testing is $750 to sequence the indicated gene in the first affected person in a family. Once a mutation is identified, the cost for the DNA diagnosis of other family members is $150 per person. **For patients with symptoms of an acute porphyria, but whose specific porphyria has not been identified, a "triple test" for the genes causing three acute porphyrias can be performed for $1750, a savings of $500 over sequencing each gene separately. Results from DNA testing are available in 3 to 4 weeks.**

Our laboratory does not accept insurance. Therefore, payment (credit card or check) must accompany the patient's blood sample. A receipt will be provided, but depending on your insurance company and policy, your reimbursement will vary and some companies will not pay for porphyria testing.

By New York State regulation, DNA testing for any genetic disorder must be ordered by a physician who also must sign the requisition form and who will receive the results. A patient must also read and sign a consent form which explains DNA testing and offers counseling.

Please contact Dr. Kenneth H. Astrin (preferable by email: **Kenneth.astrin@mssm.edu**) or telephone 212-659-6783 for the required forms (which also explain shipping requirements), to arrange for testing, and/or for additional information: Porphyria DNA Testing Laboratory, Department of Genetics & Genomic Sciences, Mount Sinai School of Medicine, 100th Street and Fifth Avenue, New York City, NY 10029-6574.

*Editor's note: In the past, it was essential that biochemical tests be performed before DNA testing could be undertaken. This was part of the research requirements of New York State before approval could be granted approval for DNA testing. Fortunately, you can now have DNA tests without previous biochemical tests. This will help the many people who for various reasons have had difficulty with their biochemical tests.*

*We want to thank our generous member who made this laboratory possible for all of us.*

# International Patient Meeting in 2008

Our goal is to host an International Porphyria Patient Meeting in 2008 like the one held in Rome last year. We would invite porphyria experts in the U.S., as well as other international experts to discuss their specific expertise in diagnosis, treatment and research. This will be the meeting of a lifetime for all of our members.

However, we cannot accomplish such a major project without your financial help and volunteerism. We need your financial support as well as your help arranging and facilitating this meeting. We hope to host the meeting in conjunction with a major physician conference in the Boston area. If you are willing to make a donation to make this meeting happen, please mark your donation *Conference*. We also need your participation as volunteers and if you are willing, please let us know. *Thanks so much.*

***You Too Can Be An APF Volunteer*** like **Lisa Kanscar**, **Grace Warfield** and **Claire Sadowniczak**. Lisa (photo left) believes it is the responsibility of everyone with porphyria to help enhance awareness and education about porphyria in their respective communities, particularly within the medical field. So each year during the National Porphyria Awareness Week, Lisa creates baskets of APF educational materials and places them in local hospitals and clinics to generate interest in the porphyrias. Lisa often mans her exhibits and distributes the brochures and answers questions from the nurses and doctors, thus generating interest in the porphyrias. You, too, can assure a healthier future by volunteering a few hours of your time and energy to educate physicians in your area.

Grace Warfield (photo center) and Claire Sadowniczak also volunteered for a very important service that affects all of us: manning the exhibit booth at the 2006 ASH Convention in Orlando, Florida, an important medical convention with 10,000 physicians in attendance. Aside from overseeing the booth, Grace has also volunteered to share her story to companies interested in the treatment of porphyria. She was the perfect candidate to teach about treatments because before she was treated with Panhematin, Grace had lengthy, life threatening attacks. However, she was able to share that her doctors were able to gain control of the attacks with Panhematin infusions, as soon as the attacks began. Giving other patients hope that there is treatment for the acute porphyrias is very important, particularly for those people who have critical attacks and need this HOPE!!!. Claire, too, has been a special supportive APF member for many years. There are several upcoming conventions. Please watch the ENEWS and volunteer if a convention is near you. You will enjoy the experience and learn a lot as well.

**Lisa (left) teaching nurses on porphyria at her hospital. Grace (middle) and Claire at the convention.**

***Global Partners:*** Members of the APF live all around the globe. It is our hope that they will soon be able to enjoy the same opportunity to communicate with one another, develop friendships, and learn about porphyria in their own language. Our first **Global Partnership** has been initiated with our friends in Brazil. In our **Global Partners** section, you will find member stories from Brazil, as well as the "For Physicians" section translation in Portuguese. We would ask our international friends to contact us if they are interested in starting a support group in their country.

***PCT Treatment*** We have discovered from our members with **Porphyria Cutanea Tarda** that many of them are being undertreated and are experiencing difficulties even after treatment or are not being able to receive the proper treatment.

We are attempting to locate people with PCT issues. If you have PCT and are willing to relate your situation to us, please contact the APF. We will be working with a PCT researcher to develop better treatment and educational materials for primary care physicians and dermatologists.

## *Emergency Room Guidelines:*

Because our members are experiencing major problems receiving proper treatment in Emergency Rooms, porphyria experts and ER doctors who are members of our Scientific Advisory Board are developing ER Guidelines. Generally, the staff in the ER will consult particular guidelines if they are available. We want to provide these guidelines to ER's around the country.

Hopefully, we will be able to educate the medical staff in the ER who are attempting to assist a patient with porphyria and yet have little knowledge about the diseases. Aside from the usual supply method to place these guidelines in the ERs, when these guidelines are complete, we ask that our members will identify their hospitals and send us the addresses. We will, in turn, send a copy of these guidelines as well as other educational materials.

It is also important for us to identify the problems and successes our members are experiencing receiving proper treatment in the ER. Recently, one of our members arrived at the ER in a very painful AIP attack, although she had had a diagnosis of porphyria from a major porphyria center. Watch the newsletter!!!!

## *When It Is Not Porphyria is Important, Too*

Dr. Janine Jagger found herself with a serious illness that no one could diagnose. Dr. Jagger is an epidemiologist and a leader in the design and dissemination of means and strategies to protect health care workers from the transmission of blood borne diseases. Therefore, she is very medically knowledgeable. In fact, Dr. Jagger is so skilled in her work that she won the McArthur Prize, one of the most prestigious awards in the world. But her career almost came to a halt when she began a strange cycle of pain and illness.

She and her doctors searched diligently to discover why she was enduring this on-going siege of pain and illness to no avail. Because her symptoms were so similar to the acute porhyrias, they decided that porphyria was the most likely answer. But like many other people seeking a porphyria diagnosis, the tests did not bear out their determination and were negative or inconclusive. Confused, sick and desperately in need of help, Dr. Jagger reached out to the APF for assistance. We showered her with educational materials and personal assistance to answer her questions and help her locate testing laboratories that could give her more reliable results. She was disappointed when both her biochemical tests and her DNA tests were NEGATIVE for porphyria. Disheartened and sick, she couldn't bear another long exhaustive search for a diagnosis.

Desiree then explained to her that many people endured this same scenario. Since porphyria symptoms are like those of so many other disorders, diagnosis through specific tests on blood, urine and stool is essential. Porphyria has several interesting names that illustrate this situation. One is "the little imitator," because it imitates the symptoms of most diseases: pain, tachycardia, blistering, rapid pulse and many others. Also, porphyria is called the "tic tac toe" disease, because some patients have had so many surgeries their abdomen resembles a "tic tac toe" board. Thus, testing is absolutely essential and relying on symptoms alone can lead to more misdiagnosis. The following is Dr. Jagger's account of her eventual diagnosis, which, hopefully, will encourage you to continue to seek a diagnosis. *A year ago I was still struggling to find an explanation for my recurrent attacks of excruciating abdominal pain that had become so frequent that I could no longer lead a normal life. Happily, I finally have an official diagnosis- Periodic Fever Syndrome, a first cousin to Familial Mediterranean Fever. I have my life back and the pain is gone. I feel very lucky.*

**Testing Quandary** We are in a porphyria testing quandary in this country. Most European countries have one or more specialized university-based laboratories that are resources for the biochemical and molecular diagnosis of porphyrias. These laboratories and associated clinical and laboratory scientists are funded largely by national governments, research and service, and they provide expertise for reliable diagnosis and specialized treatment of porphyrias throughout Europe. In some European countries, most families with inherited porphyrias appear to have been identified and their mutations are known. As a result, most gene carriers in these countries can be identified and preventive measures can be taken to avoid symptoms of porphyria.

By contrast, in the USA, where federal government funding for porphyria research has declined severely, there is only ONE university laboratory that is a resource for biochemical testing, and another that is beginning to offer DNA testing. Most porphyria testing in the US is performed by large commercial laboratories that report results which are of uncertain reliability and are often misinterpreted. Therefore, a correct diagnosis is often delayed. In Europe porphyria experts are attached to porphyria laboratories, so the experts can interpret the test results promptly. However, commercial laboratories in the USA, like Quest, do not have an expert available who can consult with the patient's primary care physician about the test results. **Dr. James Kushner** and **Dr. Karl Anderson** oversee university laboratories that offer this important diagnostic service. The DNA laboratory at Mt Sinai is now available for DNA testing; but since biochemical testing is also available, insurance companies most likely will not pay for or reimburse for this service. Thus, the patient must bear the expense of the DNA test personally.

*If you are having difficulty procuring a diagnosis because of problems with biochemical tests, you might consider DNA testing. Also proper biochemical testing often depends on the specific laboratories. For information about the nearest porphyria laboratory near you, contact the APF.*

**JOIN THE APF ENEWS . . . CONTACT THE APF TOLL FREE: 1.866.273.3635**

## Justin and His Music

**Justin Jones**, until recently, was plagued with an illusive illness that kept him in and out of school and in and out of the sports and other activities youngsters enjoy. This pattern continued through high school and into college. After a seemingly endless array of doctors, tests, and hospitalizations, Justin was emotionally and physically spent. Over time, doctors could not find any reason for Justin's consistent abdominal and muscle pain and vomiting. Justin endured the misdiagnosis and disbelief that many of you have encountered. He said that this made him feel alone and almost powerless because there were no tests that would prove that he was ill. That made the repeated misdiagnosis even worse.

Finally, a doctor acted on a "hunch" and tested him for acute porphyria. When the tests came back positive, more than a decade later, Justin felt validated. No longer could people say he was lazy or a hypochondriac as some had suspected. Now that he has a "real" diagnosis, he is trying to implement important life changes to keep his acute porphyria at bay. For Justin, changing his diet, quitting alcohol, smoking, and caffeine, and adding more carbohydrates instead of fats had a positive effect.

Fortunately, his love of music and wonderful talent gave him a helpful focus during the difficult years. Jason began playing various instruments and writing songs at an early age. Justin now writes and plays his own music and uses his musical talent to express his feelings about porphyria. He will be featured on many college radio stations and National Public Radio stations beginning this year. And, Justin received prizes and an **Honorable Mention** in the 14th Annual Billboard World Song contest for his song, *Late in the Afternoon*. Out of over 14,000 entries, his was in the top few hundred. Justin has also been notified that two of his songs, *"The Doctor"* and *"Early in the Morning"* are being considered for "Songs for the Cure" American Cancer Foundation. You can hear Justin on his web site: **www.jonjonesmusic.com**.

## Monica's Biography in Progress

Monica Bennett Firchow, the daughter of Gene Bennett, is writing a loving tribute about his life with Congenital Erythropoeitic Porphyria (CEP), which affects only 300 people worldwide. CEP can, and did in Gene's case, cause a life of suffering and severe disfigurement. For a glimpse of his life, see Monica's account of Gene's amazing and courageous story at **www.genebennett.net**.

*"I have felt compelled by a strong prompting to write my father's biography for some time. I have been obedient to that prompting by becoming a bit of a sleuth in gathering information on a life that ended almost twenty years ago. I have a binder bulging with interviews, letters, newspaper clippings, and even published medical articles with my father as the case study. ...*

*CEP causes its victims to be extremely photosensitive. Any area exposed to sunlight can result in severe phototoxic damage. Blisters form on the skin and burst, leaving open wounds that are vulnerable to secondary infections. These infections make it impossible for the skin to heal, thus causing massive scar tissue. In the worst cases, like Gene's, photomutilation occurs over a long period of time resulting in partial or total loss of fingers, earlobes, nose, and lips."* (Excerpt)

*Light is sweet, and it is pleasant*
*for the eyes to see the sun.*
Ecclesiastes 11

What happens when you have a photosensitive porphyria and cannot enjoy the beautiful sunlight? Gene's photosensitive porphyria was the very rare type, CEP. In Gene's case, he was blessed to have had world renown porphyria expert and APF advisor, Dr. Neville Pimstone, as his physician.

All of our members are fortunate that physicians, like Dr. Pimstone, are on our APF Scientific Advisory Board. That is why it is important that such expertise is not lost in the future. Please support the training of new experts through the *Protect the Future* program.

***Your gifts of time, talent and financial assistance make the programs and services of the APF possible.***

***Be a Volunteer.***

**Richard and Diane Levere**

## In Memory:

We are saddened that two of the original APF founders and members of 25 years died recently. First, **Dr. Richard D. Levere** beloved friend and porphyria specialist and researcher, died in Marietta, Georgia with his wife, **Diane**, at his side. The faculty of the New York Medical College where he served as Chairman of the Department of Medicine and its affiliated hospitals and clinics from all over the Metropolitan New York region mourn his passing.

Dr. Levere enjoyed a distinguished career in medicine, including a specialty in porphyria. He performed some of the early, life saving research on hematin therapy. He generously supported the APF, as well as porphyria research. We sympathize with his family over his loss and want them to know that we knew Dr. Levere as a very special man of kindness and great compassion who impacted our lives immeasurably. We miss him and thank God for him.

* * *

Our wonderful friend, **Barbara Young Styles**, also died unexpectedly. Since the early days of the APF, Barbara volunteered her services and helped the APF in numerous ways, despite her handicap. You see, Barbara was a quadriplegic. Yet, this did not prevent her from encouraging, helping and praying for our APF members. Barbara was a courageous, uplifting woman whose spirit was admirable and should serve as an example to us. Contact the APF for information on memorial gifts. *God's Blessings*

We also want to extend our deepest sympathy and *God's Blessings* to the families who have lost their loved ones. We also sincerely appreciate their generous contributions to the APF in their memory.
Dr. C. Robert Breckenride for ***Marnie Breckenridge***
Lois Williams and Theresa Cipiti for ***David Jones***
Carolyn Crandell for ***Colleen C. Pacific***
Donna L. Pagano for ***Arlene Yager & Millie O'Toole***
Andrea & Robert Wahlstrom for ***Clarence & Steven Sather***
Charlene Yuranek for ***Dale Yuranek***
Elaine Smuczynski for ***Helen Smuczynksi***
Maribeth Danko for ***James Smuczynksi***
Ann & Stephen Hallberg for ***Patricia A. Depukat***
Desiree Lyon for ***Dr. Richard Levere & Barbara Syles***
Rehabilitation Institute of Chicago for ***Barbara Styles***
Donald & Stephen Davidson for ***Barbara Styles***
James V. Young for ***Mary Jones***

## In Honor:

Donations to the APF have also been received by members in honor of their loved ones and friends. We appreciate their generosity.
Elizabeth A. Timper for ***Diane & George Paquet***
Sharon Koch for ***Matt Koch***
Michelle Mary Letkemann for ***Mary Cernik***

## IN TOUCH MEETIINGS

Our members expect **IN TOUCH** meetings to be educational, supportive and friendly but what most new attendees don't know is that they are FUN and events where many freindships are made!!!! Plus, it is easy to join in the camaraderie. We also need our members to host a meeting in their area. If you would like to join or host a meeting, please contact our IN TOUCH coordinator, Lelia Brougher at **email@broughers.com** or the APF on the Toll Free **1-866 APF 3635**.

## Florida IN TOUCH Meeting

I would like to share the wonderful IN TOUCH meeting I had in March at my house in Fort Lauderdale, Florida. The most amazing group of people showed up. We had eighteen in all. I thought it was so great that some family members came to the meeting to learn and be more supportive. We all had our stories to tell about our porphyria. To me it was so refreshing to know that there were more people like me out there. The people that came drove from all over the state of Florida, and I heard we had a couple from California. We had a nutrition specialist come with her client; she has been working with the carbohydrate diet for porphyria. That was great for everyone! You really have to learn how to eat all over again with the carbohydrates.

Everyone was so happy, and I believe they all felt just like me. Happy to know they are not alone. I hope to do this again. I want to educate as many as I can about porphyria so no one feels alone ever again. I believe it starts with us to host IN TOUCH meetings and teach our family and friends, doctors and nurses about porphyria. I just can't thank everyone enough for their time and love they put into the IN TOUCH meeting. And a big thanks to the American Porphyria Foundation for guiding us together and doing their best to help and educate all of the families, friends and many more that live or work with porphyria. By the way, everyone brought munchies and they were yummy!

*Sherrie Miller*

*Thanks for your many Well Wishes and Prayers during my recent surgery!*

*Desiree*

# 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.porphyriafoundation.com

### Drug Database

Many of you participated in the drug study with Dr. Peter Tishler. The resulting safe and unsafe drug list appears on the web site's home page. Many APF members responded, thus enlarging the number of medications for study. Members can still participate by informing us of their reaction to a new drug: good or bad. Please let us know for future research.

### Global Partners

The APF has always been an international organization with members from 30 countries. However, recently, we initiated a *Global Partners* program to help our international members. Brazil is our first partner with the medical information and stories translated into Portuguese. Take a look !!!

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