



Protect Our Future Physician Chosen

Your special donations have made it possible to train a new porphyria expert as part of our *Protect Our Future* program. We are delighted to announce that **Dr. Gagen Sood** has been selected to begin training at the University of Texas Porphyria Center. Dr. Sood will work for two years with Dr. Karl Anderson, a prominent porphyria expert, in research, laboratory and clinical training for each porphyria.

Dr Sood's primary interest is in liver diseases. After completing medical school and a specialty in gastroenterology in India, he became interested in the field of clinical hepatology and liver transplantation. He came to United States for a fellowship in Gastroenterology at University of Alabama at Birmingham and advance training in transplant hepatology. In 2005, he arrived at the University of Texas Medical Branch where he has focused his clinical interest in Transplant Hepatology. At present, Dr. Sood is initiating a Liver Transplant Program at UTMB.

Interestingly, at two points in his career, he has had an opportunity to work with porphyria experts, Dr. Joseph Bloomer and Dr. Karl Anderson and consequently developed an interest in learning more about the field.

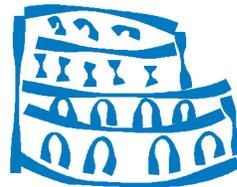
Dr. Sood resides in Galveston with his wife, Sonia, who is a family practitioner. They have two children, a son, Akhil, (12) and daughter, Alisha, (5).

We welcome Dr. Sood into the porphyria fold and appreciate his forthcoming time and effort on our behalf. Congratulations !!!!

The mission of our "Protect Our Future" campaign is to attract and train the next generation of experts in the field. Your donations have enabled the APF to secure the financial support for the first year of training. Now we need to begin to collect funds for the second year of this training program. Your help is needed to have funds for the second year of training. This program was started to help secure a healthy future for each of you, so your participation in our "Protect the Future" project is essential. Please mark your donations. "Protect Our Future," and they will be placed in that fund. Thank you

1st International Patient Meeting

THE FIRST INTERNATIONAL PORPHYRIA PATIENT MEETING will be hosted



in Rome, Italy on October 26 and 27, 2006 by A.Ma.PO, the Italian Porphyria Foundation. The director, Simona Pavia, and the medical director, Dr. Gianfranco Biolcalti invite you to attend.

The APF will be joining other porphyria organizations around the world to attend this exciting meeting. This gathering is a marvelous opportunity to meet new friends from the US and abroad. We will also have the opportunity to learn about porphyria from an international group of porphyria experts.

What setting could equal Rome, one of the world's most beautiful, historical and fascinating cities? So friends, save your money, save your airline points, save your vacation time and save your health by joining other APF members in Rome for one of the most unforgettable experience of your life.

If you are interested in attending, please contact Lelia Brougher, our meeting coordinator at 404 550-4880 or email@broughers.com.

YOU CAN BE A RADIO STAR

Desiree Lyon is being featured on the Phil Grohs-APF internet broadcast. She gives an overview of each of the porphyrias, including information on the diagnosis and treatment of this group of diseases. It is also interesting to hear the many case histories to illustrate each type, particularly since there are thousands of people who have contacted the APF for help. She even shares some of her own experiences with AIP.

Listen, too, as Desiree talks about the research transpiring on porphyria. There are several projects that need research volunteers. You can make a great impact on the disease by being a research volunteer. No treatment or diagnostic procedure can come to the forefront without your help.

Listeners want to hear your story as well. Learning about the experience of other people with porphyria is very educational. It is also interesting to learn from a person who has experienced the problem, not just read about it in medical texts.

If you are willing to share your story, please tell it into a tape recorder and then send the audio tape to the APF office for review. With your consent, we will place the story on the internet broadcast.

Check it out: www.porphyrifoundation.com.

"Ur-ine" Trouble

People often contact the office because their urine has a reddish tint, and they have abdominal pain, so they think they have porphyria. We explain that although the urine of a person with one of the acute porphyrias may be or may become a purple-red color upon standing in the light, the urine color is not a reliable diagnostic technique. In fact, urine can take on different colors for many reasons. Eating certain foods like rhubarb, beet root and blackberries can turn some people's urine red. Dark brown or tea-colored urine can also indicate infection in patients who have undergone heart or valve operations.

Urine that turns black when exposed to air can also be a sign of alkaptonuria, a rare enzyme disorder that causes abnormalities of the skin and cartilages. Gout can produce pink urine and the antibiotic rifampicin, used as an adjunct to other antibiotics and sometimes as a treatment for tuberculosis, turns urine and other secretions including tears, an orange hue. When this occurs, it means that the drug is being properly absorbed. Also, propofol, a common sedative in critical care wards, turns urine pink if given in the right dose but green if patients are getting too much. So watch carefully, because the varying shades of urine may or may not mean porphyria, but they may be a tale tell sign for some medical condition.

For Your Information

Column 1 denotes the biosynthetic pathway of heme, in which eight molecules of aminolevulinic acid (ALA) are transformed into one molecule of heme. Column 2 indicates the enzymes that catalyze the reactions and their cellular locations. Column 3 denotes the type of porphyria. Column 4 denotes the main site of the enzyme defect. Column 5 indicates the inheritance pattern. Column 6 indicates the light sensitivity. Column 7 indicates neurological symptoms.

1 Compound	2 Enzyme	3 Porphyria Type	4 Main Site of Defect	5 Pattern of Inheritance	6 Photo-Sensitivity	7 Neurological Symptoms
Glycine + Succinyl CoA	ALA Synthase (mito)	-	-	-	-	-
Aminolevulinic acid (ALA)	ALA dehydratase (cyto)	ALAD porphyria	Liver	Recessive	No	Yes
Porphobilinogen (PBG)	PBG deaminase (cyto)	Acute intermittent porphyria	Liver	Dominant	No	Yes
Preuroporphyrinogen	UPG synthase (cyto)	Erythropeoctic porphyria (Gunther's disease)	Bone marrow	Recessive	Yes	No
Uroporphyrinogen I, III (UPG)	UPG decarboxylase (cyto)	1. Porphyria cutanea tarda 2. Hepato erythropeoctic porphyria	1. Liver 2. Liver	1. Dominant 2. Recessive	1. Yes 2. Yes	1. No 2. No
Coporphyrinogen I, III (CPG)	CPG oxidase (mito)	Coproporphyria	Liver	Dominant	Yes	Yes
Protoporphyrinogen IX	PPG oxidase (mito)	Variagate porphyria	Liver	Dominant	Yes	Yes
Protoporphyrin IX	Ferrochetalase (mito)	Erythropeoctic protoporphyria	Bone marrow	Dominant	Yes	No
Heme	-	-	-	-	-	-

In Memory and In Honor

Thank you to the following members, who graciously made donations to the APF in memory of their loved ones: Ann L Hallberg for **Patricia Depukat**, Fedora and Frank Stenger, Marilyn and Arthur Ickes, Virginia & Paul Wenzel for **Mark Greenwood**, Donna Pagano for **Arlene Yager**, William S. Bell for **John T. Landon**, Elaine Smuczynski for **Helen Smuczynski**, Martha & Gordon McKinney, Gertrude & Howard Stephens, Mayetta & Family for **Lawrence "Alvie" Reynolds**, Stephen Malloy Desormeaux for **Josephine Desormeaux**, Charlotte Beck for **Gene Denger**, Nita Busby for **Karim Estephan**, James Hopp for **Anne Sheehan**, Marilyn Morgan for **Tina Moschino**.

We thank these friends who generously donated gifts to honor: Hannah Watkoske for **Mary Ann Blanchette**, Marianne P. Clements for **Desiree Lyon**, Marie Rasch and Gerald L Klamath for **Lisa Kancsar**, Judith A Phelps for **Dr. Harry Reynolds**, Bonnie R Marcus for **Dr. Kenneth Astrin** and **Dr. Karl Anderson**, Carol N Darr for **Shelly Hill**.

Latent Porphyria

A person diagnosed with porphyria will often have a number of relatives who also have inherited the altered gene responsible for the type of acute porphyria in their family. Many of these relatives may not know that they have inherited an acute porphyria gene, because they are symptom free. However, they are still at risk of developing an acute attack and passing on the acute porphyria to their offspring. Their offspring can also then have the genetic effect and may or may not exhibit symptoms. In fact, generally, only one in ten people with the acute porphyrias exhibit symptoms, which is why it is sometimes difficult to diagnose these family members.

If you have family members who have been diagnosed with one of the acute porphyrias, it is very important to be tested as well, even if you are not exhibiting symptoms. For example, not all individuals with a deficient porphobilinogen deaminase (PBG-D) develop symptoms of acute intermittent porphyria. This is an intriguing problem that may be associated with low clinical penetration or a relationship to enzyme activity. These people could still develop symptoms after taking unsafe medications, etc. These symptoms may be due to factors like heme deficiency or ALA and PBG toxicity. This also makes it difficult to predict whether certain drugs are porphyrinogenic.

Therefore, an early diagnosis of the acute porphyrias is important to reduce the risk of an acute attack. Thus, if you have one of the latent porphyrias and would like to be tested, please contact the APF.



Media Attention

The APF has made a concerted effort to gain media attention as part of our awareness program. We have had amazing success. In the past year, the following television programs have either had porphyria as their theme or have presented a porphyria patient's case history: **CNN News, Fox News, Anderson Cooper 360,**

Dr. Sanjay Gupta, House, National Geographic, Court TV, Discovery Health, BBC News, Mystery Diagnosis, Scrubs, and others.

A well as many other major journal and newspaper articles like: **Parade Magazine, NY Times, Washington Post, Health Care News, and Britannia Publications.** Your story is interesting, too, so please contact your local media and ask that they publish a piece your experience.

You Are Needed . . .

as a research volunteer for the DNA project at Mt. Sinai Medical Center, Department of Human Genetics. Contact Desiree for more information.



Porphyria Awareness Week

National Porphyria Awareness Week
February 18th-25th, 2006



Parker Snyder

Parker Snyder, who has EPP, was our youngest fundraiser for the National Porphyria Awareness Week (NPAW) and had the most unusual awareness activity. Jason and his parents set up a "National Porphyria Awareness Week" exhibit booth at the Montana championship wrestling matches. Because of the attention they received, their local television station asked to film a program on the Snyder family to illustrate how they deal so successfully with EPP. The reporter commented that the Snyders were inspirational examples of how to live in the face of adversity. If you have EPP and would like to contact the Snyders, please email jnssnyder@msn.com or contact the APF.

Health Care News

The Minnesota Health Care News, a consumer/patient guide that is placed in the waiting rooms of primary care physicians, recently included an excellent article about porphyria. This type of publication is extremely important to our physician education and awareness efforts.

If you know of a similar magazine in your area, please send us a copy or the name and address of the publication. We will then approach them to do a similar article on porphyria. Your participation in this project is of utmost importance, so please call the APF: 713 266 9617.

A Miracle Has Happened

Well, maybe it is not a miracle, but for some of our APF members, it will certainly feel like one.

Through a recent cooperative effort with the APF, The HealthWell Foundation opened an Acute Porphyria Fund. This fund is designed to assist eligible APF members suffering from acute porphyria with their out of pocket costs such as prescription drug coinsurance, co-payments, deductibles and health insurance premiums; and other out-of-pocket health care costs. If you would like information, please call the APF at **1-866-APF-3635**.



A Girl From Texas

By age twenty, Ruth Conerly hitchhiked to New York in mid-depression with only \$100. Within a year, she became one of the Big Apple's top illustrators, produced a best-selling book series and sold the largest sum in War Bonds with her illustrations. Her painting, *Death of Alamo*, hangs at the Alamo.

Dr. Sharon Wolfe, Ruth's daughter, gives an account not only of Ruth's life but also of

how porphyria led them on the most interesting quest of their lives. The account also tells of travels across continents and back into time to a mysterious death and a family legend of a prince, a future King and a Quaker girl. You can order the book via; www.agirlfromtexas.com or Antigua Odisea Publishing antiguaodisea@msn.com.

Ruth's father was a descendant of Buxton Lawn, the son from an early marriage of King George III and Hannah Lightfoot. Some of his descendents settled in Louisiana and Mississippi in early 1800. *If you are related to this family, please contact the APF as historians are interested in discovering the family mutation.*

Host An IN TOUCH Meeting

One of the best opportunities to meet other people with porphyria is to join the IN Touch network. Joining is easy. Just contact the APF and ask for a consent form. This form enables us to give and receive contact IN TOUCH information.

If you are interested in hosting an APF IN TOUCH meeting in your area, please contact the IN TOUCH coordinator, Lelia Brougher, at 404 550 4880 or email@broughers.com or return the form to the APF and indicate that you are interested in being a host. You can find this form on our website or call the office and we will send one to you.

If there are not enough members in your area to hold a meeting, we can arrange a conference call for a group. If you are interested in a telephone meeting, please contact Lelia.

Lyon's Share

Twelve Surgeries and No Colon Later

Recently, I answered a call and heard a very weak, very frightened young woman. She had just been diagnosed with acute intermittent porphyria (AIP) and had endured twelve unnecessary surgeries, including removing her colon. To compound matters, she also received misinformation in an Internet chat room, including incorrect statements about Panhematin and several renowned porphyria experts, who have voluntarily helped patients for decades and deserve our highest respect. Fortunately, she called the APF.

I first pointed her to the same expert who had been maligned. He quickly verified her diagnosis and suggested a course of Panhematin, which promptly suppressed her symptoms. Thus, she could have died if she had followed that misinformation. Her story reminds us of that we must be careful in communicating medical information.

Parade Magazine

Parade Magazine will be publishing a story on the unique difficulties of rare diseases. After reading Desiree's story, they contacted her and asked to feature porphyria and her experience with the disease. This will be published in the July 23, 2006 issue. Parade's interest is an outcome of our Media awareness program. Watch for the issue!

You Can Own a Piece of History

In response to your questions, we are relating again that we have received permission to replicate a rare hand written letter from King George III, dated February 23, 1789. Historians say it may be the one single document in English history in which medical and political history is joined, in particular George's bout with porphyria.

One of our members wrote, *"I never expected the letter to be so real or the package so elegant. We have used it as a way to discuss porphyria."* Our letter is amazingly authentic looking, suitable for framing and available for a \$50 tax deductible donation.

You can view and order the package at www.porphyrifoundation.com or call the APF. The package includes:

- An excellent replica of the original handwritten letter
- A transcription of the letter
- A brief history of King George III and the impact of his illness on the colonies and British rule
- A handsome display folder



You Can Be A Research Volunteer

*Because we have had so many questions regarding DNA testing, below is a synopsis of the last newsletter article on the subject. This is also a reminder that **Research is the Key to your cure.***

Dr. Kenneth Astrin at The Mount Sinai Porphyria DNA Testing Laboratory offers DNA-based testing for Acute Intermittent Porphyria, Congenital Erythropoietic Porphyria and familial Porphyria Cutanea Tarda. These DNA-based tests are only available to patients whose biochemical tests have been confirmed for AIP, CEP or fPCT. To inquire if you qualify for DNA-based testing and for information on sample requirements and shipping, contact Dr. Astrin at 212-659-6783 or Kenneth.astrin@mssm.edu.

If you have a confirmed diagnosis for ALA-Dehydratase Deficient Porphyria, Hereditary Coproporphyrin, Erythropoietic Protoporphyrin and Variegate Porphyria, your help is needed to establish DNA tests for these porphyrias as well. We need you to provide samples for the development of these tests. Without your help these tests cannot be developed.

The lab is also offering gene testing for AIP, CEP, and fPCT for individuals who have the biochemical evidence of enzyme assays and/or measurement of urinary porphyrin and porphyrin precursors. The gene tests for AIP, CEP or fPCT will be provided for the next six months at **no cost** to you except for the blood drawing and shipping charges. After July 31, 2006, the cost of identifying a family mutation will be \$500 and then \$100 to test each family member. Typically DNA testing takes 2 to 4 weeks.

Dr. Peter Tishler at Harvard University Channing Laboratory is researching safe and safe and unsafe medications. He is interested in your experience with medications, so please contact contact the APF or Desiree lyonapf@aol.com.

Dr. Micheline Mathews-Roth at Harvard Channing Laboratory is trying to develop safe gene therapy for EPP. She and her collaborators have cured the mouse model and will need EPP volunteers in the future.

Research and You

Our research coffers hold \$1,500. Over a decade ago, government funding for rare diseases, like porphyria became almost extinct. This leaves us in a very sad position. At the suggestion of our APF committee members, we were asked to make our members aware of this important fact. For example, there are NO government funds to support the new drug research, which is very important to each of us. Therefore, with your help, we can support research, like Dr. Tishler's.

Several members are helping us raise funds to be earmarked for research. **Jennie Eberhardt** is organizing an extraordinary piano concert in Racine, Wisconsin with Steve Hall, who is a

renowned International Steinway artist. This will be a thrilling event and a lot of hard work, Jennie welcomes your assistance. Please contact the APF.

Lisa Kanscar of Burton, MI. has a number of on-going projects for porphyria research and awareness. One of her creative tactics was to ask her local paint store to donate the paint buckets, which she decorated and set in stores she frequents regularly. She also arranged a successful fund raising drive at her daughter's school. All of our members join together in thanking Lisa and Jennie for their time and energy on our behalf.

If you would like to organize a fund raising or awareness event in your area, please contact Elizabeth or Yvette at the APF office. If you are not able to organize an event but would like to contribute toward research, please use the enclosed envelope.

Porphyria Incidence

Have you ever wondered how many people have porphyria? We don't know because there is no National Registry for porphyria. The absence of a porphyria registry in the United States impedes the calculation of our accurate incidence of porphyria.

The incidence of porphyria varies by type with Porphyria Cutanea Tarda (PCT) as the most prevalent and Congenital Erythropoietic Porphyria (CEP) the least. One of the major projects that the APF would like to undertake is to convince the National Institutes of Health to create a national registry for porphyria. However, this is a project that we cannot do without your help. We need members in the Washington, DC area to help.

Do You Need A Doctor?

Many of you have called the APF to ask us to help you locate a primary care physician. It has been the APF policy to only give out the names of porphyria specialists. By specialists, we mean the doctors who write the major medical textbook articles on porphyria, perform important porphyria research and publish articles about porphyria in major peer-reviewed medical journals, such as the *Annals of Internal Medicine* or the *New England Journal*.

Now, however, the APF, is trying to initiate a process whereby our members can call the APF, and we will then attempt to locate a primary care physician who is treating porphyria patients. If you are need of a physician in your area, please contact the APF and we will give you options to help you initiate your search.

**APF TOLL-FREE NUMBER:
1-866-APF-3635**



EPP Legislation

I would like to thank APF members for their help in securing legislation in Washington State for handicapped parking privileges photosensitive people.

This effort started when my doctor suggested that I get paperwork for handicapped

parking. If you are very photosensitive and are interested in trying to do the same in your state and would like information on the procedure, please contact me via the APF. Thanks, *David McRae*

APF Committees

Because of the enormous growth of the APF over the last few years, we need to add more means for member input. So, in addition to our existing Member Advisory Committee, the APF has instituted the following new committees. We will hold scheduled conference calls to review important issues. If you would like to join a committee, as the following members have done, please contact Lelia Brougher at 404-550-4880 or email@broughers.com.

Government Relations Committee — to engage member support for legislative issues that are pertinent to our health: *Dave McRae, Stacey Hermann, Terry Griffin, Rose Jeans*

Member Relations Committee — to build the IN TOUCH program and increase APF membership: *Jenni Eberhardt, Jenni Hubenthal, Eric Lifschitz, Karen Eubank, Roberta Feinsmith, Lelia Brougher, Danielle Frazzini*

Medical Committee — to clarify and identify issues of diagnosis, treatment and other important frequently asked questions: *Marlene Brezee, Alva Irish, Dr. Jason Chang, Dr. Luis Eraso, Phil Grohs, Suzanne Opperman, Roberta Feinsmith, Suzette Cowles*

Media Relations Committee — to enhance media attention locally and nationally: *Diane Dumaine, Sarah Lee, Mabel D'Alton, Cindy Sola, Alie Campbel, Stephanie Frazzini*

Results of the Porphozym Study

Zymenex, a Danish biotech company, developed and studied a new drug for treating acute intermittent porphyria (AIP). Porphozym is a recombinantly derived porphobilinogen deaminase (PBGD), the enzyme that is deficient in AIP. When infused by vein in the first clinical study, Porphozym markedly decreased levels of porphobilinogen (PBG) in serum and urine in asymptomatic AIP patients. Thus, this drug has a dramatic effect on the principal heme precursor that accumulates in AIP.

The next step was to study if Porphozym was effective for relieving symptoms during attacks of AIP. Therefore, Zymenex sponsored a large international study. The drug was infused by vein for 48 hours as soon as possible after onset of an acute attack, and was

followed by standard treatment. Ten patients were enrolled at two centers in the United States (The University of Texas Medical Branch at Galveston and the University of Connecticut in Farmington) and 23 patients at multiple centers in Europe. The study was placebo controlled (half the patients did not receive the real drug), randomized (the treatment was assigned at random) and double-blinded (neither the patients nor the doctors at the treatment centers or at Zymenex knew which treatment was assigned until the study was completed). Because this type of study design avoids bias, it is standard when new drugs are studied for treatment of more common diseases, but has never been done before in studying a new drug for treating porphyria.

After the study was completed, Zymenex broke the code to determine which patients received drug or placebo, and compared the results in the two groups. It was notable that some patients in both groups improved, and some did not improve and required treatment with hemin. Porphozym was demonstrated to be safe and well tolerated by all patients and, as expected, substantially lowered PBG. However, the drug was not found to have a significant beneficial effect on the symptoms of AIP, although it is possible that because of the great variability between patients with AIP, a beneficial effect may have been missed. Because the desired clinical effect was not demonstrated in this study, Zymenex has decided not to pursue further development of Porphozym at the present time.

Zymenex expresses their thanks to all the patients who provided their time and enabled the study to be completed. Those interested in knowing whether they were treated with Porphozym or placebo may contact Dr. Anderson or Dr. Bonkovsky for this and any other information. While the results overall are disappointing, there are a number of positive outcomes. The high quality of the study means that indeed, a new, high standard for studying new therapies in acute porphyrias has been set, and will positively influence how other new drugs are studied in acute porphyrias in the future. The results are very important scientifically, because they show that lowering PBG does not necessarily mean that symptoms get better. There has never been a study before that lowered one precursor selectively. The study strongly suggests that PBG is an important marker in AIP, but not the cause of the symptoms. These may be due to other heme precursors, such as delta-aminolevulinic acid or porphyrins (which are not lowered by Porphozym), or perhaps even to heme deficiency in the nervous system.

It is possible that the drug may be prepared in another form in the future, and Zymenex might partner with others to do that. Delivery of the enzyme into cells, for example, might be more effective, but would require a major redesign of the product. Other possible treatments, such as gene therapy, which delivers the missing gene rather than the enzyme, are also on the horizon. [Zymenex has supported a graduate student's thesis and several journal publications on gene therapy in AIP.](#)

The Porphozym study has set a new standard of quality in terms of study design, and has advanced knowledge about what causes symptoms in AIP. Therefore, it has been an important step in the search for better treatments for acute porphyrias.

In Touch

Many of our members have joined the IN TOUCH network but have not realized that they can request the names of other members in their state who are also part of the IN TOUCH network. Therefore, we will be sending each IN TOUCH member the names of **EVERY** other IN TOUCH member so you can all communicate. If you want to become a member of the IN TOUCH network, please return your permission form. Then you, too, will receive the list of the other members.

Staying in touch with other people who have your same illness has proven to be extremely helpful. In fact, the self help movement has become recognized in the medical community as beneficial to a person's health.

In addition, IN TOUCH members can host an IN TOUCH meeting. The most recent meeting is to be hosted on June 3, 2006 by Mira Geffner for our members who live in Southern California. Joining such a group can be play a major part in "getting well." The following people are members of the IN TOUCH network and there are many others.



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

Phil's Internet Show Recently, Desiree taped a number of case histories of people with each of the different porphyrias, as well as a bit of the history of the APF and its inner workings. Phil placed them on his *Underground Internet Broadcast*. If you would like to hear about cases similar of your own, tune in to the APF website. Please send your taped story to the APF.

With a tax deductible donation of \$25.00, you will receive one of The Acute Porphyria or EPP kits for the ER or your PCP or Desiree's book, *Porphyria, A Lyon's Share of Trouble*. or the DVD *Porphyria Live* for \$20 and The King George letter for a \$50.00 tax deductible donation.

Suggestions? Please send them to the APF.

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