eAdvocate

...your online connection to the Friedreich's Ataxia Research Alliance

Issue #1 Spring 2007

Clinical Trials Update

Several drugs that have received support from FARA are expected to be entering clinical trials beginning in the next few months. FARA is committed to working with scientists and physicians in all areas of research to foster the collaborations and partnerships and garner the resources necessary to find treatments for FA. Here is a brief status report on the most promising drugs being considered for clinical trials.

Erythropoietin (EPO) – Edison Pharmaceuticals

FARA has supported the important discovery work of the Austrian team of Drs. Barbara Scheiber-Mojdehkar and Brigitte Sturm for a number of years that has led to the findings that erythropoietin can increase frataxin in laboratory cells. The team also reported initial findings of a brief proof-of-principle study in humans at the 3rd International FA Scientific Conference. The preliminary observations from a small, open-label, proof-of-principle study of EPO in FA patients are reportedly very promising.

There is now a contractual arrangement between that team at the Medical University of Vienna and Edison Pharmaceuticals to advance EPO into FA clinical trials. Such trials are in late stages of planning and are to be conducted simultaneously in the United States and Europe beginning within the next few months, according to those preparing the plan.

This is a drug with serious, known side-effects. FARA's scientific advisors make it clear that this drug should not be used "off-label" (in diseases for which it has not been approved) and that it is absolutely necessary to wait for clinical trials to further evaluate the benefits and risks.

Continued on p. 4

In this issue:

Kyle Bryant Completes Journey

Kyle Bryant on his journey across America

"I was running on adrenalin. Forty three miles on a bowl of cereal and a power bar. Friends and family were there to meet us with balloons, banners and a shower of champagne, what a finish! I am so happy to be done and I am so glad that so many people got involved along the way." -- Kyle Bryant in Memphis

With these words, Kyle Bryant, 25, announced the completion of his 2,800-mile bike ride to draw attention and raise research funds to help find a cure for Friedreich's ataxia.

Continued on p. 3

What is Friedreich's ataxia?

Friedreich's ataxia is a life-shortening, debilitating and rare genetic neurodegenerative disorder. Onset of symptoms usually occurs between the ages of 5 and 15. Symptoms include muscle weakness and loss of coordination in the arms and legs; impairment of vision, hearing and speech; aggressive scoliosis (curvature of the spine); diabetes, and a serious heart condition. Most patients need a wheelchair full-time by their late teens or early twenties. There is no cure. Most childhood-onset patients with this disease die in early adulthood. FARA is a 501(c)(3) tax-exempt non-profit organization dedicated to supporting research leading to treatments and a cure for this relentless and devastating disorder.

President's Message

Crossing the Threshold for Treatment

Dear Friends,

We are clearly on the threshold of approved treatments for Friedreich's ataxia. We can not cross that threshold without successful clinical trials of the potentially therapeutic drugs being developed for us. We are now looking at the real prospect of having FA clinical trials of four different drugs starting this year, with at least two more following next year. Each of these promising drugs has a pharmaceutical company committed to advancing it from drug "discovery" through drug development, into clinical trials and, if successful, into our patients. Without these pharmaceutical companies, no patient organization or coalition of patient organizations could afford to move all these drugs through this important process.

At the same time, these pharmaceutical companies know they can not be successful without all of us – the FA patient community. Without all of us, they would not be able to recruit sufficient patient participants. These pharmaceutical companies know that most drug trials fail and most of them fail because of insufficient patient participation.

You will all agree that the FA community can not afford to let that happen to us. A number of these wonderfully promising drugs will be in clinical trials at the same time. We do not know which of these drugs will prove to be most beneficial. It would be tremendous, of course, if several of them prove to be beneficial and a combined, or cocktail therapy, could result that would be at the optimum dose levels of each drug so as to maximize the net benefits and minimize the net risks.

We need to make sure that each one of these clinical trials gets enough patient participants to be a valid, reliable test of each drug. If not, we could lose a golden opportunity forever – we would never know if the drug in question could provide benefit to FA patients.

The most important step to ensure that all these significant trials get enough patient participants, is to have all FA patients enrolled in the FARA Patient Registry.

Enrollment is Simple:
- *Go to the FARA Patient Registry web site: www.cureFA.org/registry/*
- *Select the "New Registrant" button at the top of the screen*
- *You will be taken through the Registry in a series of easy steps with help and instructions as you go.*

Your enrollment does not commit you to participate in any clinical trial. It simply alerts FARA to your interest in considering participation so that, when recruitment of patient participants for a clinical trial begins, your eligibility for each trial can be assessed and the physicians conducting such a clinical trial could contact you and provide you with all the information you will need to decide if you would like to participate. The decision is yours to make.

Although you will be enrolling in the Patient Registry through an internet web site, please be assured that your information will be stored in a secure database designed to protect your personal information. If, at any time during your registration process or when contacted by a clinical trial physician, you have a question for FARA, you can contact FARA's Patient Registry administrator, Jennifer Farmer, at jen.farmer@cureFA.org.

Success is in your hands. Please register today!

Warmest regards,
Ron

Mary Stuart Masterson Makes Her Directorial Debut - "The Cake Eaters" and Earns Tribeca Film Festival Spot

The Cake Eaters, written by Jayce Bartok, is the directorial debut of actress Mary Stuart Masterson; and stars Bruce Dern, Aaron Stanford, Kristen Stewart, Elizabeth Ashley, Jayce Bartok, and Jesse L. Martin. The story revolves around three men dealing with the loss of the matriarch of the family in their own painful ways: Easy (Bruce Dern) confronts a long standing affair he has been having with Marg (Elizabeth Ashley), Beagle (Aaron Stanford) gets involved with a teenager (Kristen Stewart) with a rare neurological disorder called Friedreich's Ataxia, and Guy (Jayce Bartok) attempts to reconnect with an old flame (Miriam Shor) and atone for his absence. Principal photography was completed in July of 2006 on location in Hudson and Catskill, New York; and the film is getting ready to begin its festival journey.

Tribeca Film Festival Showtimes:

Sunday, April 29
6 p.m.
Clearview Chelsea West Theater 1

Monday, April 30
6:30 p.m.
AMC 34th Street Theater 10

Thursday, May 3
4:30 p.m.
AMC Village VII Theater 2

Saturday, May 5
8 p.m.
Regal Cinemas Theater 10

Kyle Bryant Completes Cross-Country Journey to Memphis: $100,000 Raised for FA Research

Bryant left La Jolla, California, on January 22, 2007 with a group of friends and family, and logged about 60 miles a day, arriving at the National Ataxia Foundation annual meeting in Memphis on March 22. He kept a blog describing his journey http://rideataxia.blogspot.com/

Bryant later had an audience laughing and moved to tears at the NAF meeting as he described his adventures along the way. He overcame pain, fatigue, and more than 30 flat tires to complete the journey. His mother drove the van and his father and uncle road along with him.

"He had his eye on the goal, and he knew there were a lot of people he promised he was going to do this," said his father Mike Bryant, in a newspaper interview. "He was going to stick to it no matter what. It was remarkable to me."

Bryant had set a goal of raising $30,000 for Friedreich's ataxia research and exceeded his goal, raising $40,000.

The National Ataxia Foundation and Friedreich's Ataxia Research Alliance are establishing a Kyle Bryant Fund with matching grants to provide $100,000 for preclinical Friedreich's ataxia research.

Applications for the Kyle Bryant translational research grant in Friedreich's ataxia were due May 1, and the money will be awarded in June.

"There is an optimism in our community of ataxians," said Bryant. "Many people think that we can actually beat this thing. There is a lot of promising research going on, and the main thing that the researchers and scientists need to push their treatments through is more money."

Bryant began his journey at the Scripps Research Institute in La Jolla where a team has developed HDAC inhibitors that, in test cells, reactivate the frataxin gene responsible for Friedreich's ataxia. Along the way, Bryant also made stops at facilities in Phoenix, Houston, and New Orleans where researchers are engaged in basic research and developing compounds for possible treatments of Friedreich's ataxia.

There have been a number of promising developments in Friedreich's ataxia research in recent years. Six Friedreich's ataxia clinical trials are planned in the U.S. and Europe over the next year or so. ■

Kyle Bryant is honored by NAF Executive Director Michael Parent

Kyle Bryant with his mom Diane, dad Michael, and Ron Bartek

Kyle Bryant with his dad and uncle

Kyle Bryant Translational Research Award

Friedreich's Ataxia Research Alliance and the National Ataxia Foundation invite proposals, under a competitive Request for Applications (RFA) process, to award a grant focusing on pre-clinical investigations that will facilitate clinical trials for Friedreich's ataxia. We anticipate funding one award for one year under this program. The total award is limited to $100,000 (direct costs only). Applications are due by May 1, 2007.

RFA:
www.curefa.org/docs/kyle_bryant_tra_rfa.pdf
Application:
www.curefa.org/docs/kyle_bryant_tra_app.doc

Clinical Trails Update (continued from p. 1)

Deferiprone - Iron Chelator - ApoPharma

It has long been known that iron accumulates excessively in the mitochondria of FA patients and is implicated in oxidative stress and cell death. Scientific collaborations around the world have led to interest in an iron chelator called deferiprone, which is a drug approved for use in Europe for treating thalassemia. Dr. Arnold Munnich in France has been conducting a small, open-label, pilot study of deferiprone, and reports encouraging preliminary observations. The drug company that owns deferiprone, ApoPharma, has been working with such FA researchers and FARA to plan a Phase II trial expeditiously.

This, too, is a drug with serious, known side-effects. FARA's scientific advisors make it clear that this drug should not be used "off-label" (in diseases for which it has not been approved) and that it is absolutely necessary to wait for clinical trials to evaluate further the benefits and risks.

Idebenone – Santhera Pharmaceuticals

Dr. Nicholas Di Prospero and his colleagues at the NIH National Institute of Neurological Disorders and Stroke (NINDS) completed a Phase II trial of Idebenone in FA in the fall of 2006. Those investigators concluded that Idebenone appears to be safe and well tolerated. They also reported that, although the changes they observed in the patients in this short trial did not achieve the level of "statistical significance," the changes did show "a trend toward dose-dependent effects on neurological outcome measures," suggesting Idebenone has possible therapeutic value in treating FA.

A Phase III trial in the United States is being planned for this summer. FARA is told that the Phase III trial in Europe is underway and that Santhera is preparing to file with the European regulatory agency for Idebenone marketing permission based on the data already obtained in the NINDS Phase II trial.

EPI-A0001 - Edison Pharmaceuticals

The latest estimate available to FARA is that a trial of EPI-A0001 should begin within the next few months, possibly in Europe first and then elsewhere, as European regulatory agencies reportedly have some prior experience with this compound. Edison Pharmaceuticals reports that the preclinical development and testing of EPI-A0001 continue to yield extremely encouraging results.

MitoQ - Antipodean Pharmaceuticals

FARA is told by the MitoQ team that the U.S. Food and Drug Administration (FDA) had questions about the adequacy of safety data collected on MitoQ in animals and wanted the MitoQ team to conduct more testing in that regard. The MitoQ team indicates that it is targeting early 2008 for commencement of a Phase II trial of MitoQ in FA.

HDAC Inhibitors – Repligen Pharmaceuticals

Research in patient cells and mice indicates that a class of compounds called Histone Deacetylase (HDAC) inhibitors increase production of the frataxin protein, which suggests potential utility of these compounds in slowing or stopping progression of the disease. Data supporting the ability of this class of HDAC inhibitors to increase production of the protein frataxin was published in Nature Chemical Biology (August 20, 2006 online). This research was led by Dr. Joel Gottesfeld, professor of molecular biology at The Scripps Research Institute and supported in part by FARA. The compounds developed by Dr. Gottesfeld are the first HDAC inhibitors to demonstrate utility in increasing the level of frataxin protein in preclinical models of Friedriech's ataxia. Preliminary data from Dr. Gottesfeld's lab also suggests that this class of HDAC inhibitors might have utility in treating other disorders such as spinal muscular atrophy and Huntingdon's disease.

Repligen Corporation announced April 11th 2007 that it has entered into an exclusive commercial license with the Scripps Research Institute for intellectual property covering compounds, which may have utility in treating Friedreich's ataxia. The Scripps research was funded in part by grants from the Friedreich's Ataxia Research Alliance (FARA).

The Treatment Era Needs YOU!

These clinical trials being planned around the world are the vanguards of the treatment era for Friedreich's ataxia and a range of related disorders. We will not be successful in achieving treatments without these clinical trials. These clinical trials will not be successful if we do not all pull together to assemble the funding and the patient participants each trial will require. Please help by getting all FA patients enrolled in FARA's Patient Registry and by helping, in any way you can, to assemble the financial resources that will be necessary. ■

Get Signed Up in the Patient Registry Database for Future Clinical Trials:
Visit www.cureFA.org/registry/

Pamela Rasey Joins FARA as Marketing and Development Officer

Pamela Rasey joined FARA's team as Marketing and Development Officer in December of 2006. Her primary goal is to seek support from philanthropists, corporations and foundations as we move towards treatments and cures. Pamela is driven by her own passion for a cure as she watches her 10-year old nephew, and many close friends and families, manage the on-going challenges of Friedreich's ataxia and its progression.

This role was formed as a result of advancing translational and clinical research that requires much more funding than basic research for trials and drug development. Grassroots fundraising, coupled with new corporate and individual donations, will allow FARA's research program to grow and ensure that new treatments continue to enter the research pipeline.

Fundraising Results

Since December 2006, $710,000 has been raised through corporate fundraising development. The fundraising goal for 2007 is $3 million. With the support of FA Board Members, patients and families, partners, new angel donors and communities, Pamela is on a continuous search for contacts that could provide referrals, networking and funding. The highest rate of successful asking and giving has been when a contact is aware of a family's specific situation or where there is a personal relationship with the desire and passion to help in some way.

Ongoing Support Moves Research Forward

Timing is critical. FARA scientists and researchers are on the edge of finding treatments and cures. With your help, we will cross the finish line! Sample types of donations are shown below. Contact us with your ideas, new contacts or companies.

One-time donations
2-3 year donation commitments
Stock donations
Endowments
Company sponsorships for events
FARA as charity-of-choice for a company or event
Family fundraisers
Planned giving
Memorial gifts
In-kind gifts
Cause-related marketing
Matching gift programs
Referrals and networking

Special Thanks to New Angel and Corporate Donors:

Mr. Robert Basham
Mr. James Bauchman
OSI Restaurant Partners, Inc.
Standard Meat Company
Kingston Companies
InsideOut Sports & Entertainment
Berman and Company

Contact Information

pamela.rasey@cureFA.org
(513) 659-8203

ATTENTION CYCLISTS (and others!)

Paul Monson, friend of the Hartigan family (Ashley, 11, FA) has jerseys for sale (prices and shipping costs below) in honor of Kyle Bryant and to help support FARA research, where all funds will be allocated. Paul donated his time to creating the design for the shirts and obtaining sponsors in support of all of those families dealing with Friedreich's ataxia. He is the owner of Lithoflex (Sacramento, CA). The jersey sale will be ongoing.

Men's Sizes: XS, S, M, L, XL, XXL, XXXL
Women's Sizes: XS, S, M, L, XL, XXL

Short Sleeve Jersey $55.00
Long Sleeve Jersey $60.00
Shipping: $6.00

Please send checks (payable to FARA Research) to:

FARA Research
c/o Litho Flex Co.
Freeport Blvd
Sacramento, CA 95822

(916) 393-4256

Clinical Trials Fuel Preparations for "Friedreich's Ataxia Awareness Day" May 19, 2007

THE SENATE
OF THE
COMMONWEALTH OF KENTUCKY
2007 Regular Session
Senate Resolution No. 120
Monday, February 26, 2007

Senator Richard L. Roeding introduced the following resolution which was ordered to be printed.

A Resolution recognizing the third Saturday in May as Friedreich's Ataxia Awareness Day.

Friedreich's ataxia patients and families have many reasons to welcome the approach of "Friedreich's Ataxia Awareness Day" on May 19th. The third Saturday of May is recognized in Congressional and state proclamations and through various events around the country as "Friedreich's Ataxia Awareness Day."

An extraordinary explosion of research insights has followed the identification of the Friedreich's ataxia gene in 1996. Now, only 11 years later, there is increasing conviction that treatments will soon be developed for Friedreich's ataxia and that the resulting insights will be broadly applicable across a wide range of neurological disorders such as Parkinson's, Huntington's, Alzheimer's, ALS and a number of rarer diseases as well.

This growing conviction and the accompanying excitement are based on the fact that this year there are plans for six clinical trials of drugs that show tremendous promise for treating Friedreich's ataxia for the first time.

Friedreich's ataxia scientists and patient families alike are confident, in fact, that these clinical trials, and others that are to follow, will result in the first treatments for this disease. Because such clinical trials are far more expensive than the basic research from which they grow, the "Awareness Day" events being planned across the country this year are more important than ever.

In Kentucky, State Senator Richard "Dick" Roeding introduced a proclamation that was passed by the Senate and House. "Currently, there is no cure for the disease. But, raising awareness of Friedreich's ataxia will lead to more research and a greater understanding of the disease, and hopefully, a cure," said Roeding. ■

Contact our Development Officer with Corporate, Foundation or Individual Donor ideas:
pamela.rasey@cureFA.org

Grassroots Fundraising 2007

Before we tell you about our 2007 events, we have one more from 2006 we want to recognize. Dan Olsen of Monroe, NJ, has held very lucrative golf tournaments over the past few years, all to raise money for FA research. This past year Dan raised $42,000! Thanks go to Dan and his community of supporters. Your hard work will mean further progress for the researchers who will be receiving these funds.

We started off the year with a number of FUN events. Thanks to all of our event planners, with funds directed to either FARA or to Seek A Miracle/MDA. All of our collaborative efforts are "paying off" and are bringing us closer to our goal of treatments or a cure. Your support for the FA researchers is cherished by all.

Portage, Indiana
In honor of the Hook family, Dave Morris and Brad Crosby organized an event that included chili, a bake sale, music and a game of Left – Right – Center. The grand total for the event was $6,675 thanks to all of their thoughtful and generous donors. Dave and Brad say they are willing to share the recipe for the delicious white chili made by "Mike and Mike". Contact FARA at fara@curefa.org and we'll send that off to you.

Continued on p. 7

Jerry, Brad, Dave, Michelle and Emilie

Singer Kelly entertains the guests at the chili party

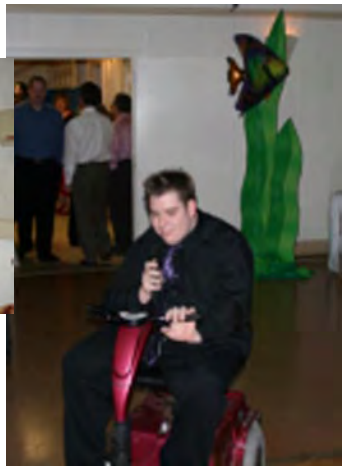
New Philadelphia, Ohio

Sandy Parrish and family, of New Philadelphia, Ohio, raised $22,000 for Seek a Miracle/MDA in the Stride and Ride in their area. As many of our readers know, the Parrish family has been very active in fundraising over the past few years and has encouraged many others to do the same. Sandy is a great cheerleader!

Sterling Heights, Michigan

The Haldeman family went "Under the Sea" to raise over $14,000 for research. Their dinner/dance event included a Treasure Box raffle. A friend made the beautiful boxes complete with the top saying "Haldeman's Hope Chest". Thanks, Haldeman family and friends!

Tanner Halderman



Jesse Halderman

Santa Clara, California

The Rupel family held their annual FAITH event and raised over $40,000 to be used to support our FA scientists. Nearly 200 supporters were greeted at the door with Mardi Gras masks and beads. They enjoyed dancing and music, including that of the "Quadrupels". In Bart Rupel's letter to the FAITH event attendees, he quoted Mason Cooley who said, "Faith moves mountains, but you have to keep pushing while you are praying." Matt Rupel was featured in a number of very informative articles in the Santa Clara Weekly and you can read more about the FAITH event in the follow up article at http://www.santaclaraweekly.com/308.html.

Thank you, Rupel family. You've inspired us all. As Bart says, "Let's go move that mountain!" ■

More FAITH pictures on p. 9

Request a Fundraising Kit Today!
Visit www.cureFA.org

Upcoming Events

If any of you out there are interested and able to attend these upcoming events, please contact either FARA or the family planning the event for further information. Those who plan fundraisers welcome more participation, particularly when it includes those families of someone with Friedreich's ataxia.

May 19 6th Annual Walk for Hope and a Cure
Orange, California
Contact Sandy Lane: typesandy@aol.com

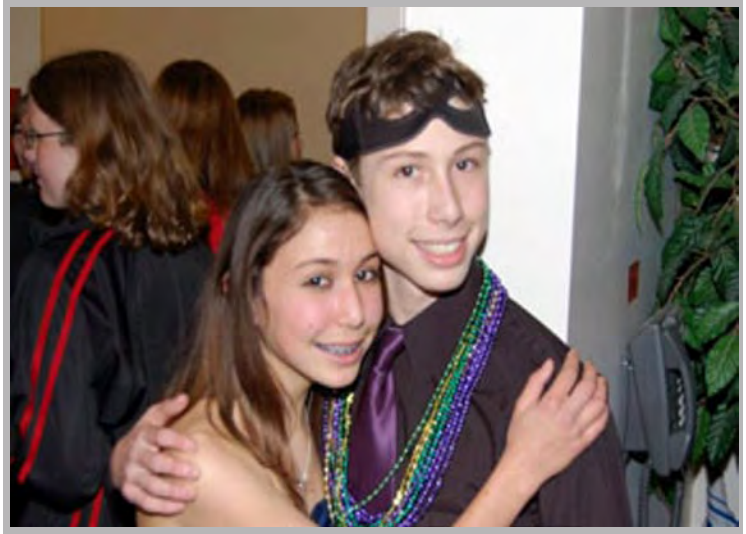
May 19 8th Annual Walk to Seek A Miracle
Rochester, New York
Contact Margaret Ferrarone: margaret.ferrarone@eds.com
Contact rochesterdistrict@mdausa.org
(585) 424-6560

May 18-19 Golf, "Funraiser", Auction/Band Benefit
Bogart, Georgia
Contact Nelda Van Schoick: neldasvs51@yahoo.com

May 20 Cincinnati's Race for a Cure
Cincinnati, Ohio
Contact Tammy Luebbe: TAMMYLUEBBE@aol.com

May 27 Walk and BBQ
Bakersfield, CA
Contact Carrie Laird: keyedup@bak.rr.com

May/June (date TBA) Voyces Concert
New York City, NY
Contact Brian Wurschum: www.thevoyces.net
Listen to/Order their CD at:
http://music.barnesandnoble.com/search/product.asp?r=1&ean=793447104928



Matt and Katie Rupel at FAITH 2007

FARA Awards Six Grants Exceeding $600,000 in the 1st Quarter 2007

We continue to receive excellent research proposals from FA scientists around the world. FARA accepts grants on a rolling basis throughout the year and, in the first three months of 2007, we have awarded six grants and we have another four currently in the review process. FARA and MDA have partnered to fund several of these grants. Specifically, MDA is a partner in the Collaborative Clinical Research Network for Friedreich's Ataxia.

Grants Funded in 2007

Principal Investigator	Project	Research Area	Category	Outcome
*Joseph Sarsero	Development of pharmacological therapies for FA using humanized mouse models	Basic/Translational	Animal Model and Drug Screening	↑ frataxin
Pook/Gottesfeld	Histone Deacetylase Inhibitor (HDACI) therapy of a Friedreich's ataxia mouse model	Translational	Drug Development	↑ frataxin
*David Lynch	Collaborative Clinical Research Network for Friedreich's Ataxia	Clinical	Clinical Outcome Measures, Biomarkers and Trials	All
*Grazia Isaya	Modulators of frataxin assembly: assay development for high throughput screening	Translational	Drug Screening	All
Robert Wilson	Supplement to previous FARA grant and RO1 to support high throughput drug screening	Translational	Drug Screening	All
Marek Napierala	Influence of chlorambucil-conjugated GAA-TTC sequence-specific polyamides and Histone Deacetylase Inhibitors (HDACI) on repeat instability and frataxin expression	Basic/Translational	FRDA gene	↑ frataxin

** Grants co-funded with MDA.*

"Research Area" refers to three broad categories of research -- basic, translational and clinical. Basic research is the most fundamental and explores the underlying causes and mechanisms (pathophysiology) of the disease. Translational (or preclinical) research advances the results of basic research from discovery through development, from "bench to bedside." It involves, for example, testing drug discoveries in animals and human cell cultures in preparation for tests in humans. Clinical research involves trials in humans. The "Category" column is used to characterize the focus of each research project. The "Outcome" column places the goal or long-term benefit of each project into one of four categories – Determine Pathophysiology, Improve Mitochondrial Function (↑), Reduce Oxidative Stress (↓), or Elevate Frataxin Protein levels (↑).

As we continue to receive and award research grants in 2007 we are striving to maintain a balanced portfolio of grants. We want to fund a variety of research in different categories that will lead to research and medical advances for FA and identify novel treatments. Specifically, we are funding less basic research and more translational and clinical studies to accelerate the development of treatments. ■

Fundraising Across the U.S.

(FAITH pictures continued from p. 7)

Do these wild revelers look familiar?

The night was filled with music

Dr. Guy Miller from Edison Pharmaceuticals, Guest Speaker

FARA Board & Directors

Ronald J. Bartek, President, Director, Co-Founder
US Military Academy, BS; Georgetown University, MA

Bronya J. B. Keats, Ph.D., Chairperson, Scientific Review Committee, Director Australian National University, Professor & Head of Department of Genetics, LSU Health Sciences Center, Director, LSU Center of Excellence in Molecular & Human Genetics, New Orleans, LA

Massimo Pandolfo, MD, Scientific Review Committee, Director
Chef de Service, Service de Neurologie H'al Erasme, Universitibre de Bruxelles, Belgium

Bernard Ravina, MD, Scientific Review Committee, Director; Chief, Mind Unit; Clinical Trials Coordination Center, University of Rochester

Paul Avery, Director, Corporate and Institutional Relations
Kean University, COO, Outback Steakhouse Inc., Tampa, FL

Mary Caruso, Director, Fundraising
Small Business Owner, Northford, CT

John Cubbin, Director
Lawrence Institute of Technology & Wayne State University; VP & Enterprise Client Executive, EDS, Rochester, NY

Terrence Downing, Treasurer
Canisius College, BS Accounting, Certified Financial Planner and Certified Public Accountant, Buffalo, NY

Marilyn Downing, Fundraising, Secretary, Director
St. Joseph College, BS, Special Education State University of New York College, MS, Exceptional Education, Special Education Evaluator, Erie County, NY

William Hartnett, Director, Information Technology
B.A., Franklin & Marshall College, Program Manager, EDS, Rochester, NY

Nicholas A. Johnson, Director, Public Awareness and Organizational Liaison Senior Mechanical Engineer, Bard, Rao + Athanas Consulting Engineers, LLC, Boston, MA

William Krutzer, Director, Strategic Planning
Louisiana State Commissions, Monroe, LA

Sandy Lane, Director, Fundraising
B.A. Psychology, Small Business Owner, Orange, CA

Paul Marcotte, Director, Public & Media Relations
BA University of Wisconsin, JD Chicago Kent College of Law, Communications Consultant

Samantha Litke Wilson, Director
Seek A Miracle (SAM), Cherry Hill, NJ

Jennifer Farmer - Grants Administrator and Patient Registrar, Genetic Counselor/Study Coordinator, Children's Hospital of Philadelphia
La Salle University

Pamela Rasey, Development and Marketing Officer
University of Dayton

Raychel Furr Bartek, Co-founder, Executive Assistant, Patient-Family Liason
U of Louisiana @ Lafayette

Of Counsel
Laura Kalick, Attorney at Law, Washington, D.C.
Milton Cerny, Attorney at Law, Washington, D.C.

Contact Us

Friedreich's Ataxia Research Alliance
P.O. Box 1537
Springfield, VA 22151

Phone: (703) 426-1576

E-mail:
fara@cureFA.org

Web Site:
http://www.cureFA.org