

## Grant Program Update

By Jennifer Farmer

### FARA and Partners Award 11 Grants Exceeding \$900,000 in the First Half of 2007

The Friedreich's Ataxia Research Alliance (FARA) Grant Program accepts grants on a continuous basis throughout the year from FA scientists around the world. All grant applications go through a scientific peer-scientific review process to ensure that FARA funds the most critical research.

In the first half of 2007, FARA awarded 11 grants, which exceed \$900,000 in funding. There are another six grants currently in the review process that will require an additional \$500,000 if found meritorious.

FARA partners have helped make these grant awards possible. Without your support and donations to FARA, funding FA research and advancing our mission to identify treatments and a cure for FA would not be possible.

Other foundations are also committed to advancing FA research and we have been able to partner with them in making several of these grant awards. We would like to recognize our partners from: Muscular Dystrophy Association; National Ataxia Foundation; and the Friedreich's Ataxia Research Alliance – Australia/New Zealand.

*Acting alone, there is little we can accomplish but working together, there is little we cannot achieve.*

More Grants info on p. 9

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## Grassroots Fundraising



Les Goldstein prepares to get soaked at a FARA fundraiser held in Glenview, IL on behalf of Alena and Alisa Wolfson (p. 10)

By Marilyn Downing

Spring is the most eventful season when it comes to FARA fundraising. This May and June there were a number of repeat performances and new fundraisers.

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### 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.



Dear friends and partners,

With five different, potentially therapeutic drugs lining up for imminent clinical trials in FA, we all know how important it is that we get every shoulder to the wheel to move these trials across the finish line successfully. With your support, FARA has worked hard to assemble and nurture the public-private partnerships that were extremely important in the basic-research era and are absolutely essential in this clinical treatment era. You have always been an important partner in this effort. It will become clearer and clearer to you, now, that you are the MOST important partner.

A tremendous public partner from the beginning has been the U.S. Government. The National Institutes of Health (NIH), who helped to inspire FARA's founding, has provided insightful advice and ready encouragement. They also have frequently funded grants to FA scientists who applied for large NIH grants on the basis of preliminary results under FARA "seed grants."

FARA has been invited to participate in FDA meetings, on behalf of pharmaceutical companies seeking approval of FA clinical trials, and to testify before congressional appropriators regarding the need to increase government support for medical research.

Corporate shoulders have also been brought to the wheel. In some cases the corporations themselves and, in other cases, individuals from the corporations have become major donors to FARA. In another case, a major corporation, EDS, has significantly accelerated FA research by providing the invaluable volunteer services for IT solutions such as FARA's Patient Registry and Data Management for the clinical network. This network was first established to develop clinical measures for FA trials and is now evolving into the network of centers where the clinical trials will be conducted.

A number of other foundations have also partnered with FARA to help advance FA research. Some, like the Muscular Dystrophy Association, National Ataxia Foundation, and FARA's partner foundations in Europe and Australia/New Zealand, are drawn to this powerful partnership because they share our commitment to develop treatments for FA. Others, like Cure Huntington's Disease Incorporated, are now investing their resources to develop the same drugs (those of Edison Pharmaceuticals) because they too, see tremendous potential benefit from them.

However, no foundation or group of foundations, acting alone, has the resources and expertise needed for drug

development, clinical trials, drug approval and drug marketing. Always recognizing that fact, FARA has been fortunate to develop partnerships within the pharmaceutical industry that have resulted in the planning of five drugs for clinical trials. These drug companies are partnering with FARA and with you for a number of reasons. In several cases, they know that with your support, FARA has already funded the basic research that resulted in the drug "discovery" and that the drug company does not have any "sunk costs" in that regard. They also see that FARA and its partners have set in place the infrastructure needed for drug development and clinical trials – the patient registry, Collaborative Clinical Research Network for Friedreich's Ataxia, the FA rating scales to measure clinical progress, animal models, and a communication system with FA patients and their families and supporters. The drug companies also know that the leading cause of failure in clinical trials is lack of patient participants. So, the drug companies advancing FA drugs into clinical trials know that they need continued support from FARA and continued support from you. You know that we need the drug companies to get these drugs developed, tried, approved and marketed.

These partnerships are accomplishing so much and you are a central partner. Please help us get all patients enrolled in the FARA patient registry and prepared to participate in these exciting clinical trials. Also, please help FARA assemble the additional resources needed to continue supporting the research that will soon result in the first FA treatments

Warm regards to you and your families,  
Ron

## Giving Options

There are many ways to support the critical work FARA helps to fund. Here are a few examples:

- | <b>Individual Donors</b>  | <b>Corporate Donors</b>   | <b>Additional Support</b>  |
|---|---|--|
| <ul style="list-style-type: none"><li>• Yearly donations</li><li>• One-time donations</li><li>• Stock donations</li><li>• Planned giving</li><li>• Memorial gifts</li><li>• Family fundraisers</li><li>• Family foundations</li></ul> | <ul style="list-style-type: none"><li>• 2-3 year donation commitments</li><li>• One-time donations</li><li>• Stock donations</li><li>• Specified grants</li><li>• Sponsorships</li><li>• Cause-related Marketing</li><li>• Matching gift programs</li><li>• In-kind gifts</li></ul> | <ul style="list-style-type: none"><li>• Referrals to other companies or individuals</li><li>• Service donations (celebrity tie-ins, marketing or technical services)</li><li>• Foundation Grants</li></ul> |

## FARA Gains TV Coverage in New York, Philadelphia and Chicago

FARA is receiving coverage on three TV programs airing in New York, Philadelphia and Chicago.

### **New York – Keeping Kids Healthy – Channel 13/WNET with Satellite Distribution – Dates TBD**

Tami Yager, a free-lance producer, is doing a thirty-minute show about FA and FARA on a Public Broadcasting station in NYC to be aired this fall. The award winning show, called “Keeping Kids Healthy,” is in its seventh season, as a weekly pediatric health television series produced by Montefiore Medical Center in association with Thirteen/WNET New York. Check the FARA Web site in the near future for upcoming dates.

Three FA families were filmed for the program: Norm and Debra Simpson with Donovan in Rye, NY; Mary Caruso with Sam and Alex Bode in CT, and Mary-Lisa Orth and Alex in AZ. Ron Bartek, FARA President, Dr. Rob Wilson of the University of Pennsylvania and Dr. David Lynch of Children’s Hospital of Philadelphia rounded out the key representatives on the FARA, research and medical sides.

### **Philadelphia – In Focus – Channel 17 – Broadcast August 25, 2007 at 6:00 a.m.**

“In Focus” is a 30-minute public affairs program hosted by Steve Highsmith that is broadcast to 2.9 million homes in the greater Philadelphia region. A variety of subjects are covered from week to week. Programs have focused on major elections in Pennsylvania and New Jersey, medical issues such as the liability crisis, Lyme disease and autism, property tax reform, the “right to work” movement, stem cell research and more.

The unique opportunity to do a segment on FA and FARA came through with a connection to Sandy Lane, FARA Board member and mother of Chelsea. Her cousin, Vince Giannini, is VP and General Manager at myphl17, Home of MyNetworkTV. Vince graciously offered us the chance to create awareness for FA through the In Focus show that was televised August 25th.

One individual with FA was featured, Matt Duca from Coatesville, PA and key participants were Ron Bartek, FARA President, Dr. Rob Wilson of the University of Pennsylvania and Dr. David Lynch of Children’s Hospital of Philadelphia.

### **Chicago – You and the Law – CAN TV & Comcast Cable**

“You and the Law” is a 30-minute discussion program produced by the Chicago Bar Association that is broadcast on CAN TV in Chicago and Comcast cable in the Chicago suburbs.

FARA President Ron Bartek was interviewed by FARA board

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### **Kyle Bryant Translational Research Award**

In our last newsletter we told you about a courageous and determined young man, Kyle Bryant, who raised over \$40,000 for FA research. The National Ataxia Foundation and Friedreich’s Ataxia Research Alliance put Kyle’s hard earned funds to work by establishing the Kyle Bryant Translational Research Award with matching grants to provide \$100,000 for preclinical Friedreich’s ataxia research. A request for proposals was announced to the FA research community and applications were accepted through May 1, 2007. Ten exceptional grant proposals were received and peer-reviewed however; only one award could be made.

The recipient of the Kyle Bryant Translational Research Award is Dr. Nuri Gueven of the Queensland Institute of Medical Research. Dr. Gueven, in collaboration with Dr. Mark Pook of Brunel University in England, will test a novel antioxidant that has shown promising results in ataxia telangiectasia in an FA mouse model.

Title: Use of novel catalytic antioxidant, CTMIO, in a GAA repeat mouse model of FRDA

Abstract: Cellular stress through an excess of oxygen radicals is a well established feature of Friedreich’s Ataxia (FRDA) and therefore antioxidants are an obvious possibility to try and curtail disease progression. However, while some antioxidants have been shown to be effective in preventing heart problems in animal models and FRDA patients, the compounds tested had very limited effects on protecting the nervous system. One reason for this could be that the neurodegeneration in FRDA is not caused by oxidative stress. However, a more likely explanation is that the compounds used in these studies might not have reached the brain cells at concentrations high enough to be effective. Therefore, developing compounds that are not only effective in removing radicals at low concentrations but also can reach the brain cells represents a promising therapeutic approach for FRDA. We are planning to test a novel catalytic antioxidant (CTMIO) in a mouse model of FRDA. Our previous data show that CTMIO was very effective in preventing neurobehavioural problems in a mouse model of another form of ataxia (ataxia-telangiectasia) that is also characterized by oxidative stress. We therefore consider that CTMIO is capable of alleviating the neurological problems that characterize the FRDA mouse model we are planning to use. A protective function of CTMIO would represent a crucial first step in the development of novel, highly active antioxidants that could lead to an effective treatment option for FRDA.

member Paul Marcotte on a program focusing on legal resources available to families with children with disabilities. The program also featured Jeannine Corderero an attorney and parent of a child with a disability and Barry Taylor, Legal Advocacy Director for Equip for Equality, a non-profit legal organization which assists people with disabilities. The program will air this fall. ■

**FARA Video: New Tool Available for Fundraising and Awareness**

FARA is pleased to announce a new promotional video that will educate the general public about FA and how they can take action to help further research and find a cure. Our hope is that this short video will create interest and ignite a “tell-me-more” feeling when people watch it.

The video will be used in the following ways:

- Posting on FARA’s Web site home page for easy viewing and sharing [www.cureFA.org](http://www.cureFA.org)
- As a fundraising tool: Please show this video at your next event as an introduction or a running video.
- At private parties to gain support
- Raising awareness by educating, and creating a connection with individual and corporate donors
- Sharing with media contacts such as local newspapers, magazines and TV stations to introduce them to FA and FARA
- And, anywhere else we can gain exposure!

To obtain a DVD copy for a fundraising or awareness event, please contact Marilyn Downing [Mdown4@aol.com](mailto:Mdown4@aol.com) or (716) 626-0274. Please share the video with family, friends and co-workers that might be interested in learning more about Friedreich’s ataxia.

Pamela Rasey, Development Officer  
513.659.8203  
[pamela.rasey@cureFA.org](mailto:pamela.rasey@cureFA.org)

**Outback Steakhouse Offers FA Families Blimp Rides**

In 2007, Outback Steakhouse’s Bloomin’ Onion I Airship began flying the friendly skies across the United States providing aerial coverage for youth sports leagues in targeted cities. The Airship flies over local parks to capture photos of games in action. As a bonus, parents, coaches and fans then download their aerial photos online.

**Bloomin’ Onion 1 Airship takes flight with FA families**



*Steve and Penny Haldeman, Detroit*

**About the Airship**

The Outback Steakhouse Bloomin Onion I Airship is 130 feet long, 38 feet wide and 45 feet tall. It contains 68,000 cubic feet of helium, weighs 4,400 pounds, and can carry three passengers and one pilot in its 14 foot long gondola. Two Limbach L2000 engines, each developing 68 horsepower help the Airship cruise at 35 mph, with a maximum speed of 55 mph. Bloomin’ Onion I can climb 1,600 feet per minute up to a cruising altitude of 1,500 feet and a maximum altitude of 5,000 feet. The Airship is constructed of laminated polyester synthetic fabric and plastic film.

*The FARA eAdvocate is brought to you by:*

*Editors: Paul Marcotte, Ron Bartek, Pamela Rasey, Jennifer Farmer, Marilyn Downing*

*Advisors: Mary Beth Kosmicki, Bill Hartnett*

*Design/Layout: Meg Giaconia*

## Collaborative Clinical Research Network for Friedrich's Ataxia

The Collaborative Clinical Research Network in Friedrich's Ataxia (CCRN in FA) is a network of clinical research centers that work together to advance treatments and clinical care for individuals with Friedrich's ataxia. The network collaborates with pharmaceutical companies, government agencies and other research centers along with the patient community to facilitate clinical research and trials needed to identify new therapies.

Core objectives of the network include:

1. Identifying and validating clinical outcome measures and biomarkers in FA. These measures tell researchers if patients are better, worse or the same over time or in response to drug treatments.
2. Facilitating faster implementation and delivery of clinical trials. A network of physicians, nurses and support staff that understand FA, and have an established network of FA patients, will be able to implement clinical trials much more quickly. This reduces time in training sites, patient recruitment, mobilizing resources, and costs.
3. Sharing data and resources to advance treatments for FA. Every clinical research study or trial will yield data that will be important to FA researchers and the patient community. Collaboration, sharing of data and resources such as DNA samples or equipment, will allow subsequent studies to move forward faster and more efficiently.
4. Defining best clinical practices for FA and providing the highest level of clinical care for patients. Physicians and medical professionals participating in the network are experts in providing medical management to individuals with FA and are translating research into clinical practice to improve outcomes for FA patients.

At each clinical research center, there is a team of researchers, physicians, and healthcare providers that are dedicated to FA.

The CCRN in FA needs your help. Please contact a center near you by emailing the study coordinator to find out what research studies are ongoing. All sites are currently enrolling individuals with FA into natural history and clinical outcome measure studies. This research is critical to planning clinical trials (see #1 above).

The CCRN in FA is funded by the Friedrich's Ataxia Research Alliance and Muscular Dystrophy Association.

### CCRN in FA

Network Principal Investigator: Dr. David R. Lynch  
 Network Coordinator: Jennifer Farmer, MS, CGC,  
[farmerj@email.chop.edu](mailto:farmerj@email.chop.edu)

### Sites:

Children's Hospital of Philadelphia, Philadelphia, PA  
 Principal Investigator: Dr. David Lynch  
 Coordinator: Jennifer Farmer, MS, CGC  
 Contact: Jennifer Farmer  
[farmerj@email.chop.edu](mailto:farmerj@email.chop.edu)

University of California Los Angeles, Los Angeles, CA  
 Principal Investigator: Dr. Susan Perlmutter  
 Coordinator: Sakena Patterson  
 Contact: Sakena Patterson  
[SJPatterson@mednet.ucla.edu](mailto:SJPatterson@mednet.ucla.edu)

University of Chicago, Chicago, IL  
 Principal Investigator: Dr. Christopher Gomez  
 Coordinator - Elizabeth Shaviers, CCRP  
 Contact: Elizabeth Shaviers  
[eshavier@neurology.bsd.uchicago.edu](mailto:eshavier@neurology.bsd.uchicago.edu)

University of Minnesota, Minneapolis, MN  
 Principal Investigator: Dr. Khalaf Bushara  
 Coordinator: Diane Hutter, RN  
 Contact: Diane Hutter  
[dhutter@umphysicians.umn.edu](mailto:dhutter@umphysicians.umn.edu)

University of Iowa, Iowa City, IA  
 Principal Investigator: Dr. Kathy Matthews  
 Coordinator: Carrie Stephan, RN  
 Contact: Carrie Stephan  
[carrie-stephan@uiowa.edu](mailto:carrie-stephan@uiowa.edu)

University of Rochester, Rochester, NY  
 Principal Investigator: Dr. Bernard Ravina  
 Coordinator: Cheryl Deeley  
 Contact: Cheryl Deeley  
[Cheryl\\_Deeley@urmc.rochester.edu](mailto:Cheryl_Deeley@urmc.rochester.edu)

University of Texas Medical Branch, Galveston, TX  
 Principal Investigators: Drs. Tetsuo Ashizawa and Sub Subramony  
 Coordinator: Penny Stanton, CCRP  
 Contact: Penny Stanton  
[pstanton@utmb.edu](mailto:pstanton@utmb.edu)

University of South Florida, Tampa, FL  
 Principal Investigator: Dr. Teresa Zesiewicz  
 Coordinator: Kelly Sullivan, MSPH  
 Contact: Kelly Sullivan  
[kbarber@health.usf.edu](mailto:kbarber@health.usf.edu)

Murdoch Childrens Research Institute, Victoria, Australia  
 Principal Investigator: Dr. Martin Delatycki  
 Coordinator: Cate Wilson, MPH  
 Contact: Cate Wilson  
[cate.wilson@mcri.edu.au](mailto:cate.wilson@mcri.edu.au)

Emory University, Atlanta GA  
 Principal Investigator: Dr. George Wilmot  
 Coordinator: Sue Gronka, RN  
 Contact: [sgronka@emory.edu](mailto:sgronka@emory.edu)

By Mary Caruso

Having always been an optimistic person, I guess there are perks to everything. My family would never have experienced meeting and helping Mary Stuart Masterson with her film, *The Cake Eaters* if it hadn't been for living with the disease Friedreich's ataxia (FA). The communication with Mary Stuart happened quickly and, at first, I did not realize who I was speaking to even though I know many of her starring movies like *Fried Green Tomatoes* and my favorite *Benny and Joon*. You don't expect a movie star to contact you directly. After a few emails, we were off to New York to meet Mary Stuart, actor Jeremy Davidson, her brother Peter Masterson and Jesse Scolaro for interviews to assist the cast and crew with their research for FA.

Living with FA, my daughters Sam and Alex Bode take on each day of their lives with unbelievable courage and many challenges. They overcome things that we too often take for granted. I don't mean just walking, I mean simply trying to maneuver a glass of water to their mouth, trying to reach for a fork or trying to get enough breath for a whole sentence. And doing these intricate daily tasks takes up all of their energy. You can only imagine how empowering it was for my girls to work on a movie project like this. And as a mother, how rewarding it was for me to see them contribute to something and feel great about it. It also helps that Mary Stuart Masterson turned out to be one of the most kind and compassionate people we have been graced to meet! Her insight and patience was so genuine! We had a blast spending time with them while they interviewed us and asked some pretty personal questions.

We also spent time on the set during filming where we were introduced to Aaron Stanford and Kristen Stewart. They were just as kind as Mary Stuart. The fact that all these amazing people came together (a cast stitched together by Mary Stuart) seemed like a warm blanket over our family as this movie came together. It was a little over a year that we were all involved thus the excitement mounted for us as the premiere drew near.

Watching my daughters being involved with this movie was extremely emotional for me. There are many life experiences that this disease has stripped away from the girls and any involvement at all is just icing on the cake. To see how their participation and input contributed to the movie was overwhelming! Mary Stuart invited us to participate in Q&A sessions after the screenings to share the reality of the disease with the audience. We were also lucky enough to meet the Jayce Bartok, who wrote and starred in the movie. His vision in writing a character who has FA is incredibly inspiring.

Sam and Alex reveled in seeing how accurate Kristen

Stewart (Georgia) was in portraying the symptoms of the disease. They were touched to see that Aaron Stanford play such a kind and compassionate man and how wonderfully he responded to Kristen's character. As a mom who wants as normal a life as possible for her daughters, I had such a sense of relief seeing someone like Aaron's character on screen! He brought so much emotion to the part. Mary Stuart took an extremely devastating disease and showed the world a sensitive and realistic look at coping and living with it, and, for that, I am forever grateful! I will always remember this experience as one of enjoyment, enlightenment and a special opportunity for us all.

As a member of a national organization called Friedreich's Ataxia Research Alliance (FARA), I am grateful that this movie can help call attention to this disease. FA is a rare, genetic neurodegenerative disease that is recessive, which means that most people don't know they carry the gene and 1 in 100 people are carriers. The disease is progressive and there is no treatment or cure today. Symptoms like severe scoliosis, heart trouble, balance problems, diabetes, speech, vision, hearing difficulty, and more, typically begin appearing between the ages of five and 15. FARA is an organization driving research worldwide to slow, stop and eventually reverse the symptoms of FA. We are on the edge of breakthroughs.

With this disease, you have a small window to see your child grow up perfectly healthy then boom! It all starts to fall apart. Worse yet, you try to teach your child to cope with the devastation at such a young age when coping skills haven't even been developed. It is a tragedy yes, but with the continued work of FARA and people like Mary Stuart Masterson and her wonderful cast and crew, there is hope. We continue to forge ahead and bring knowledge, awareness and funding out to the world. Together we will conquer this disease and when we do, Mary Stuart Masterson will be at the top of my list as someone who played an integral part. ■



Sam, Mary, and Alex Caruso

**The Power of Networking**

Networking and sharing of contacts has been a critical source of new donors to FARA. In the fundraising world, it comes down to “asking” for support and thinking outside the box to all those you may not have considered in your network of contacts like: the company you work for, your neighbor’s employer, your local bank, and more. Many corporations today have established giving programs, matching donation incentives or are willing to be a key sponsor for a fundraising event. With FARA’s research entering the treatment era, the cost of drug development, testing new compounds and administering clinical trials takes the need for financial resources beyond that of basic research. We are in “translational research territory” that requires new levels of funding (millions of dollars to succeed vs. thousands). Contact us with your business, friend and family network so we can expand our network of donors. We welcome new ideas.

**Fundraising Momentum**

Since our Spring eAdvocate Newsletter, an additional \$225,000 has been raised from individual and corporate donors. Funding from the corporate side alone is just over \$1.2 M, in total, since December 2006.

When grassroots totals are added to that amount, FARA has received over \$1.6 million to keep research efforts moving forward. We have a goal of \$3 million for 2007 and with a strong push over the last quarter and support from our FARA community, we will get there and hopefully go beyond that amount.

Pamela Rasey, Development Officer  
[pamela.rasey@cureFA.org](mailto:pamela.rasey@cureFA.org)  
 513.659.8203

**FARA Fundraising** (continued from p. 1)

For those who are considering hosting an event, know that FARA is here to help you. Please notify FARA if you are planning a fundraiser, as we have a new fundraising form. This provides FARA with details on how we can help and it assists us in our record-keeping.

FARA is able to support your event by offering a FARA banner, video, brochures, advice on press releases and a FARA representative at your event when possible. We will work with you on the bookkeeping tasks that go along with any event. FARA has also been trying to rally support from local families near each event in order to increase attendance. Hopefully we can continue to encourage more of that, as

our FA families are so willing to support each other’s efforts. You can download FARA’s Fundraising Made Simple from the Web site or we can send a hard copy to your home.

Read about the families that have taken the initiative to hold a fundraiser. Most want to do it again! Contact: Marilyn Downing, FARA Board Secretary

**California**

**Orange, CA** The Lane family held their sixth Walk for Hope and a Cure in Orange on May 19th, which was FA awareness day (always the third Saturday in May). There



*Pre-walk warm-up.*

were attendees from Connecticut, New York, Argentina, Virginia, New Hampshire, Illinois, Mexico and Hollywood! The amazing Lanes and their amazing friends and family raised \$137,000 for Friedreich’s research. Steve and



*Ron Bartek inspires the walkers.*

Sandy Lane’s daughter, Chelsea, 14, has FA. Sandy is on the FARA board and continues to be an inspiration to many others from around the country raising funds for FA.

**Bakersfield, CA**

Jerod Laird is a college student with FA. His mother, Carrie,  
*Continued on p. 8*

received his blessing to organize a fundraiser in his honor in their hometown of Bakersfield, California. Many of our children with FA are not ready to have so much attention drawn to them but ultimately discover that both the attention and the awareness brought to them and to FA are very uplifting. The event was a 10K ending in a BBQ combined with that of their church. "There were about 200 people who actually walked or ran in the 10K, and there were approximately 600 to 700 people at the BBQ...I am really pleased, especially considering the fact that we only started planning three months ago", said Carrie. In her words, they "hit the ground running". They actually raised over \$16,000 and are already are beginning to plan their second annual. Thanks, Jerod and Carrie, for stepping up to the plate.



**Alameda, CA**

On August 4, the Bennett/Konanz/Rupel/Acker-Hitta FA families once again orchestrated their highly successful annual "Sunset on Friedreich's Ataxia." The gala included wine tasting, dinner, magic, auctions, music and dancing and was held at the Rosenblum Winery in Alameda. Paul Konanz writes: "It WAS a great evening! We had about 190 Rosenblum-tasting, VintageCatering-snacking and Outback-dinner-eating guests enjoying a very nice late afternoon and evening with a great flow of events!" There is now an additional \$70,000 for our researchers to utilize, thanks to the SOFA planners and participants. Special thanks go out to the non-FA parents on the SOFA committee that put in a whole lot of work "just because" they care. Check out [www.sunsetonfa.org](http://www.sunsetonfa.org) in the near future for photos of the celebration.

**Florida**

**Gainesville, FL**

We should all be inspired by Karla and Dan Wooten's flexibility. The Wootens planned the 1st annual Walk for Hope for the first weekend in June. From Karla's email: "Tropical Storm Barry decided to show up on the day we were supposed to walk! We still had about 100 people show in torrential rain. Much of the campus is covered so we did an impromptu walk around the campus under the covered walkways. This took about 20 minutes. We moved the function indoors and got creative. Then we came back and ate (Chili's Restaurant catered for free!!!!). We had a local orga-

nization painting the kids faces and making balloon animals which they loved. We then did our raffle prizes and silent auction. We made over \$4,000 in under 2 hours. I learned a whole lot about fundraising; like make plans for an alternate date or location in case it rains after six months of drought! I was overwhelmed at how many people still actually came out to support us in a tropical storm. The power of love is an incredible thing!"

The Wootens have some very loyal friends! The group managed to raise nearly \$4,500 for research to help their son, Joshua, 10, who was just diagnosed this past January. They are a very energetic group and are considering a casino night for this fall. That will be a new one for FARA, so stay tuned.

**Georgia**

**Bogart, GA**

Nelda Van Schoick and family, including her two girls with FA, Robbi and Becca, held a two day event on May 18-19 in Bogart, GA. Holding a golf tournament, "funraiser" and auction they raised \$58,000. This is more than triple the amount they raised in 2006! Nelda writes, "I continue to be humbled by what other people do for you when they see you making an effort. We are fortunate to have many good friends and a wonderful neighborhood." All of us are fortunate that the Van Schoick family can throw such a fun party! Special thanks to Med-Pharmex of Carrollton, TX, for their very generous support.

**Savannah, GA**

Lindsay Ashman (FA), her friends and family once again held her LOCO's Walk and Day for FA. The LOCO event, with food, silent auction, wing-eating contest and music was held on June 3rd, whereas the walk had to be postponed until June 23rd due to rain. Even with the weather as a factor, more than \$17,000 was raised by those who came out to reinforce their unending support for Lindsay! Photos here include travelers Robin and Laura Beth from Atlanta and Dylan from New York having fun with Lindsay. Lindsay said they "got to know each other better and traded FA secrets."





## 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
Filip Lim & Richard Wade-Martins	Neuron - validated approaches for developing Friedreich's ataxia therapeutics	Basic / Translational	FRDA Gene	↑ frataxin
Des Richardson	Iron Chelation Efficacy of Novel PCIH Iron Chelators In Vivo and their ability to prevent the pathology observed in the Conditional Frataxin Knockout Mouse.	Translational	Iron chelation / Drug Screening	All
#Nuri Gueven	Use of a novel catalytic antioxidant, CTMIO, in a GAA repeat mouse model of FRDA	Translational	Antioxidants	↓ oxidative stress and ↑ mitochondrial function
Arnulf Koeppen	Friedreich's ataxia: Iron dysmetabolism in the central and peripheral nervous systems	Basic	Pathology & Iron Metabolism	Elucidate Pathophysiology
^Martin Delatycki	Supplement to Collaborative Clinical Research Network for Friedreich's Ataxia – Australia site	Clinical	Clinical Outcome Measures, Biomarkers and Trials	All

\* grants co-funded with MDA, # grant co-funded with NAF, ^ grant co-funded with FARA-Australia/New Zealand

"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 FARA continues to receive and award research grants in 2007, there will be a continued focus to maintain a balanced portfolio and to advance the most promising treatments to clinical trials. FARA wants to ensure that leading candidates have the resources for drug development and that there are multiple candidates in the pipeline for advancement. ■

**In Memory...** Since the beginning of 2007, \$43,000 in memorial donations have been received. Each donor receives a note of thanks from FARA and the family of the deceased is informed of the names of all donors. We thank those who think of FARA at such a difficult time.

Memorial donations were received in memory of the following individuals: David McIntyre, Helga Montgomery, David Stambaugh, Paul Robinson, Thomas Barnett, Mary Lou Harrison, George Kobler, Annie Gulliver Reed, Betsy Neyland, Robert A. O'Neil, Sr., Deacon Joseph Orth, Benjamin C. Raymond, Jr., Josh Robiero, and Raymond Sojka.

**Illinois**

**Glenview, IL**

Alena and Alisa Wolfson are the daughters of Les Goldstein's first cousin. Both girls have FA. Les held his first annual FA fundraiser in Glenview on July 28th. There was music, a karaoke contest, a "No-Hands" Pie-Eating Contest, a Magic Show, dunking booth and silent auction. The Wolfson family produced a video in which Alena and Alisa described their experiences living with ataxia. Paul Marcotte, FARA board member, praised Les and other participants for their hard work and described some of the scientific research underway. The new FARA video was also viewed and was "very well received". The event raised around \$17,000 with more donations coming in as we go to press.

**New York**

**Tonawanda, NY**

Alisa (Lizzie) McFarland of Tonawanda was 14 when she lost her battle with FA in December of 2006. Debbie Binko, Lizzie's advocate from school, had spoken often to Alisa about holding a fundraiser in her honor. In April, Debbie held a silent auction, raising money for research to help others in Alisa's memory. All felt Lizzie was there in spirit!

**Pittsford, NY**

Once again on FA Awareness Day (May 19, 2007) the MDA staff and friends of the Ferrarone family organized their Walk to Seek A Miracle in Pittsford, NY. This is the eighth time this group has come together to show their support for those in the Rochester area with FA, including Sara and Laura Ferrarone. With help from the generous Rochester folks the walk netted \$75,000 toward Friedreich's research through the Muscular Dystrophy Association, one of FARA's partners.

**North Carolina**

**Charlotte, NC**

Thomas Barnett had some close friends at Elon University, where he was a student. Tracy Rood, along with her sister, Jamie, wrote the following in their fundraising letter: "A few months ago, we decided to begin training together to run a half marathon held in Charlotte, North Carolina on April 14th, 2007. While in the process, we began to realize how fortunate we were to even be able to participate. This led to our decision to complete this race for a greater cause and we hope that you will be able to help."

Their letter continues, "Over the past three years, while attending Elon University, Tracy has been an attendant and friend to a fellow student, Thomas Barnett. During Thomas' time at Elon he was a digital art major in the Honors Program. In October, Thomas suffered a catastrophic stroke



*Tracy and Jamie Rood.*

precipitated by the declining heart function engendered by Friedreich's Ataxia (FA)... Both of us have decided to run the race on behalf of Thomas... We believe with the combination of our family and friends we can make a difference for people who are living with FA."

Tracy and Jamie raised over \$3,000 for FA research, with help from Elon students and family and friends from New Jersey, the Rood's home state. Sadly, Thomas passed away in June. Tracy spoke at Thomas's memorial service in Chapel Hill. The hope is that the research funds the Rood girls raised will help Thomas's sister, Joanna, who also has FA.

**Ohio**

**Cincinnati, OH**

Another event on FA awareness day was the Luebbe family's annual walk and silent auction in Cincinnati. Evan Luebbe, who has FA, is eleven years old. The Luebbe's family and friends raised a generous \$33,500 to be put toward FA research. Thanks, Cincinnati folks, for doing it again for us! Since Evan's diagnosis, the Luebbes have raised \$96,500!!! That includes three walks, wine tasting and a letter campaign. The awareness that has been raised is "priceless".



*Evan Luebbe in charge on the microphone.*

*Continued on p. 12*

## EDS Grant

## FARA Board & Directors

### EDS Foundation Awards \$40,000 Grant to Friedreich's Ataxia Research Alliance

The EDS Foundation has approved a \$40,000 grant to the Friedreich's Ataxia Research Alliance (FARA) to fund the organization's Web site redesign and upgrade, as well as enhancements to its patient registry. Both projects will build upon technologies created and supported by EDS volunteers and will facilitate FARA's mission of education and advancement in treatments and a cure for Friedreich's Ataxia. This marks the first year that the EDS Foundation has supported FARA.

"We are thankful that the EDS Foundation has become the largest sponsor of this project, which will help us redesign our Web site, and also facilitate recruitment for clinical trials through our patient registry," said Ron Bartek, president of the Friedreich's Ataxia Research Alliance. "This information technology solution will increase FARA's access to key audiences and support a growing technical infrastructure that has been developed by EDS volunteers and for which FARA is extremely grateful."

The EDS Foundation was created to support EDS' philanthropic efforts in communities where employees volunteer and work around the world. Since its inception in 2000, the EDS Foundation has donated more than four million dollars to 86 nonprofit organizations. "Our board of directors was pleased to provide a grant to FARA and six other worthy organizations during its April meeting," said Diane Spradlin, executive director of the EDS Foundation. "We are delighted to add FARA to the long list of nonprofit organizations we support, as they represent a cause that EDS employees are passionate about and provide countless volunteer hours to."

The EDS Foundation supports nonprofit organizations involved in education, health & human services and arts & culture. The majority of foundation funds will be directed to these organizations in support of the productive use of technology in programs and processes. The remainder of the funding will be directed to general program support. All programs funded by the Foundation must have a current EDS employee volunteer partnership. ■

Get Signed Up in the Patient Registry Database for Future Clinical Trials:

[www.cureFA.org/registry/](http://www.cureFA.org/registry/)

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, Université 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 Liaison  
U of Louisiana at Lafayette

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

**Pennsylvania**

**Pittsburgh, PA**

Ashlea Wiegand worked along with her local Max & Erma's restaurant to raise money for FARA. 20% of all sales on May 10th went toward FA research. Ashlea and her supporters enjoyed the food—and the company. The staff at Max & Erma's were very helpful and Ashlea said they "can't wait to do it again!"



*Ashlea and her supporters.*

**August 18, 2007 — Backyard Bash, Harrisburg, PA**

We are anxiously waiting to hear the results of Francine and Pete Welsh's Charity Backyard Bash at their home in Harrisburg, PA. They planned a basket raffle, silent auction and a 50/50 drawing. There were plenty of food and drinks and their brother-in-law, John Levis, sang and played acoustic guitar.

**Canada**

**St. Albert, Alberta**

Joel Kleine, an FA'er with two young children, has some generous and athletic friends. John Luth and friends ran a marathon this summer in Alberta, Canada, hoping to move along the research that will help stop Joel's progression. Over \$2,000 was raised in that effort.



*Bro Golf Association Event.*

**Vancouver, BC**

The Bro Golf Association (BGA) has been raising money for FARA since 2001 with their annual golf tournament. In June, the generous members raised \$11,000 in memory of Rosie, who suffered from FA. Pete Bugnatto writes: "Please accept this and future donations on behalf and in memory of our dear lost friend Jeff, "Rosie" Rosencranz, son of Mike and Elaine Rosenkranz. Rosie will always be a very special part of the BGA. We hope that by continuing to raise funds in his name to support FARA, eventually a cure will be discovered and we'll need to figure out a new group to donate to (our goal is to put you out of business)." The tournament is held in a different North American location every year and includes a variety of auction items. "Between mulligans, side bets and the auction, we were once again able to crack into the five figure range when it came to what we proudly raised for FARA", writes Pete. ■

**See Page 13 for Upcoming Fundraising Events!**

**Upcoming Events**

**September, 2007 — Dinner & Raffle, Arlington, VA**

Julie Cernosek, whose brother has FA, is planning a restaurant event and raffle for the fall. ([cernosja@gmail.com](mailto:cernosja@gmail.com)). The Cernosek family is related to Brian Wurschum of the Voyces ([www.thevoyces.net](http://www.thevoyces.net)) who held the January concert in New York City, raising money for FA research.

**September 9, 2007 — Fuzzy Buzzy Golf Tournament, Windham, NH**

Erin O'Neil's Uncle Paul is once again holding his Fuzzy Buzzy golf tournament in Massachusetts. Last year's event raised over \$11,000. For further information you can contact Erin's mom, Mary Ann O'Neil at [MDay485@aol.com](mailto:MDay485@aol.com), or Paul Staniech at [pstan6767@comcast.net](mailto:pstan6767@comcast.net). Web site: <http://www.fuzzybuzzycharitygolftournament.com/fuzzybuzzy.html>

**September 21, 2007— Dinner Dance, Branford, CT**

This will be the fifth annual fundraiser for FARA in Branford, CT. Mary Stuart Masterson will host the event again this year and the Owenego Inn will offer their beautiful ocean front facility for the event. Outback Steakhouse will treat the guests to their wonderful food, and music will be provided. A live auction will take place during the event for those who wish to bid on exciting items such as New England inns, ipods and wine.

The guest list includes actors Jeremy Davidson and Aaron Stanford as well as other potential surprise guests! Mary Caruso, organizer and mother of FA'ers Sam and Alex, asks all to "wear your heart on your sleeve as the theme again is stressing the importance of acceptance and ways to make the world a kinder and gentler place for all!"

**September 23, 2007 – Jarden Westchester County Triathlon, Rye, NY**

From Jennie Sinnott: "...34 ATHLETES participating! Four individuals and 10 relay teams. Like last year, Debra (Simpson) will swim and Norm (Simpson) is biking, and this year Norm's brother, Mike, will run. It's a family affair. My husband, Aaron is going to bike and I will swim, too. This team has just exploded in size and everyone is very excited.

We also should reach an important milestone this year... Since 2004, we have raised about \$90,000 for FARA and early in the fundraising for this year we should reach the \$100K mark! Everyone is looking forward to the big race day, but we are just as excited about raising more money than ever for FARA this year."

**November 17, 2007 – Stephanie's Hope Holiday Boutique, Valencia, CA**

The members of the Magness family have become experts at event planning over the past year and a half and they are ready to take on another event. The Holiday Boutique will be held at Tesoro del Valle Elementary School and the vendors will be donating 15% of their sales to FARA. "It is our hope to double sales from last year, step up our advertising, and educate more people about FA and FARA. Last year we had 17 vendors, this year we will have 20", says Sharon, whose daughter, Stephanie, has FA.

**September 24, 2007 -- NYC concert**

Once again, Brian Wurschum of the Voyces is going to be holding a benefit concert for FARA. Brian and his band have a new CD called Kissing Like It's Love. Check out the Voyces Web site at [www.thevoyces.net](http://www.thevoyces.net). The September 24th concert is at The Cutting Room at 19 West 24th St. in New York City and all are invited!

**October 7, 2007 — The Bullpen Open Golf Tournament, Saratoga Springs, NY**

Jason Krogman, whose friend's son has FA, is organizing his first FARA golf tournament in beautiful Saratoga Springs. For further information, e-mail [carried@adelphia.net](mailto:carried@adelphia.net).

**November 3, 2007—Dinner dance, Rochester, NY**

Dave Brown's ten year old son, Alec, was diagnosed this year with FA. Dave, who has had some fundraising experience in the past, is busily planning a big event at the Rochester Airport Marriott. It will include two bands, food and drinks, and a silent auction. To get further info, email Dave at [kdacbrown@earthlink.net](mailto:kdacbrown@earthlink.net). We know there are many FA families in Western NY and we hope some of those families will be able to participate.

**Ride Ataxia, Spring, 2008**

Kyle Bryant is planning to do it again! In 2007 Kyle raised \$43,000 which stimulated a matching \$100,000 grant from FARA and the National Ataxia Foundation (see page 3 for more info). Kyle is still energized and wants to do it again! In March 2008 Kyle will be riding into Las Vegas for the NAF conference. Details to follow... ■

**Request a Free Fundraising Kit**  
<http://www.curefa.org/fundraising/>

## Last Look

August 5 -10, 2007

Five families joined Splore and some amazing volunteers and together braved Utah's Cataract Canyon.

Each family has children affected by Friedreich's ataxia. Here are some highlights of the trip.

Enjoy!



More Cataract Canyon pictures can be found at:  
[http://web.mac.com/simpson4us/iWeb/Site 2/Rafting trip.html](http://web.mac.com/simpson4us/iWeb/Site%20/Rafting%20trip.html)

## Contact Us



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

Phone: (703) 426-1576

E-mail:  
[fara@cureFA.org](mailto:fara@cureFA.org)

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

