The Advocate

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FARA Friedreich's Ataxia Research Alliance

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From the Executive Director

Meet Team FARA

By Jennifer Farmer, MS, CGC

Team FARA is a new program to raise funds and awareness while individuals reach physical goals and increase endurance. It is also how we, the FARA staff, view ourselves — as a unit. The FARA staff embodies Team FARA. Not only have we participated in Team FARA events and physically moved our offices this year one box at a time…but we are a team in the truest and most fundamental actions. We have a lean team; there are no bench-warmers. Each staff member has a specific area of focus, but there is a lot that we each do to support each other in our roles and accomplishing FARA's strategic initiatives. We currently have an annual operating budget of >3.5 million (3.2 million going to research grants and programs) and a staff of five full time members and three part-time contractors.

The FARA Staff: Jen Farmer, Felicia DeRosa, Kyle Bryant, Jamie Young, and Ron Bartek sport their Team FARA jerseys before participating as part of Team Donovan in the Jarden Westchester Triathlon.

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In this issue:

Update on FARA's Research Grant Program

By Bronya Keats, MD

FARA's commitment to funding high quality research projects that move us closer to effective treatments continued at an accelerated pace in 2011. Over the past year, 29 new grant applications were submitted and after rigorous peer review, 13 were funded. In addition, based on excellent progress, FARA provided continuation funding for 18 existing projects. In total, FARA funded 31 grants amounting to approximately $2.8 million, and it is anticipated that funding will be awarded for up to six more grant applications before the end of 2011.

These funded projects address numerous important research questions that directly target FARA's strategic research initiatives, including improved functional measures and biomarkers for clinical trials, advances in gene and cell therapy approaches, improved tools for drug discovery, and evaluation of candidates to advance to the treatment pipeline. Several are co-funded with our Friedreich's Ataxia (FRDA) advocacy group partners; this collaborative approach both increases the number of available research dollars and helps to minimize duplication of effort.

Among the particularly promising research funded by FARA is the work by Dr. Sid Hecht at Arizona State University. He is synthesizing compounds known as multifunctional radical quenchers (MRQs) and testing them in FRDA cell and animal models to determine their potential as treatments for FRDA. MRQ compounds are designed to blunt

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What is Friedreich's ataxia?

Friedreich's ataxia is a debilitating, life shortening, degenerative neuro-muscular disorder. Onset of symptoms can vary from childhood to adulthood and can include loss of coordination (ataxia) in the arms and legs; energy deprivation and muscle loss; vision impairment, hearing loss, and slurred speech; aggressive scoliosis (curvature of the spine); diabetes mellitus; and a serious heart condition. While the mental capabilities of people with FA remain completely intact, the progressive loss of coordination and muscle strength in FA leads to motor incapacitation and the full-time use of a wheelchair. There is currently no treatment or cure for FA. FARA is a 501 (c) (3) tax exempt, non-profit organization dedicated to supporting research that will improve the quality and length of life for those diagnosed with Friedreich's ataxia and will lead to treatments that eliminate its symptoms.

President's Letter

Dear friends,

This will be the most immodest president's message so far. I really feel the need to brag about all of us — about you, FARA, and the whole FA family.

Over the past couple of months, we have been constantly reminded of how unique we all are and I would like to share a few of those reminders with you. A couple of them came at the FA Symposium near Philadelphia in October. For five hours before the Symposium's opening reception, the six scientists who are leading the FA effort in stem cell research met to share their findings, decide on next steps, and assign tasks in promptly taking those steps together. Near the meeting's conclusion, the scientists thanked FARA for assembling them from Europe, Australia and the United States because, "it is only when we meet face-to-face that we feel free to share the unpublished results that are so exciting and will lead to so much more rapid progress." Then, referring to the fact that FA has these six labs in advanced stages of growing nerve and heart cells from stem cells derived from the skin cells of FA patients — and doing all that in full collaboration with each other — they added, "other diseases just don't have this."

Along the same lines, on the next day of the Symposium, one FA parent asked the scientists why it is that FA scientists seem to work together so well whereas research in other diseases seems to be characterized by competition and infighting. The FA scientists replied that the reason is that FARA has, from the beginning, established the environment of full and open collaboration toward the common goal.

Also in October, the International Conference on Rare Diseases was held in Washington, D.C. and brought together officials of the National Institutes of Health and the Food and Drug Administration, leaders of pharmaceutical companies around the world, and rare disease patient advocacy organizations. The conference organizers had selected FARA to tell its story to present a model of what can be accomplished with passion and commitment against all odds.

You all know that FARA's story is your story and that, together, we have changed the landscape of the FA community. From a sparse and scattered field of research scientists, no clinical trials, no interested drug companies, and FA families that were isolated and hopeless, we have all created a community of hundreds of collaborative scientists, the helpful involvement of government agencies, active participation of more than a dozen drug companies conducting a growing number of clinical trials, and a global FA patient family that is confident we will all achieve our goal of treating and curing FA.

Participating in the International Conference on Rare Diseases were drug companies that had only recently joined the FA community, bringing exciting new FA drugs into our pipeline. These new pharmaceutical partners made it crystal clear that they had been drawn to FA because they saw how much the FA community had already accomplished. They saw that FARA and FA families had put into place so much of what the companies need to be successful. We have funded the basic, discovery science that presents them with a mature orchard of opportunity. We have established the necessary infrastructure for FA drug screening and for the all-important clinical trials. Very importantly, they know that FA families and their friends are doing everything possible to support this effort by raising the awareness and resources needed for the research, enrolling in the FARA patient registry, and setting records for the speed of recruitment for clinical trials. The net result is that they see that FARA and the FA community have grown the mature, low-hanging fruit they are seeking. A specific example of one such pharmaceutical company is Viro Pharma, which recently announced the licensing of the OX1 compound for development in the treatment of FA.

Again, FARA's story is your story. Because we are doing all of this together, we know our story will have a happy ending.

Warmest regards,
Ron

Acting alone, there is very little any of us can accomplish.
Acting together, there is very little we will NOT accomplish.

Ron Bartek is FARA's Co-Founder and President. Ron focuses his efforts on building partnerships with government agencies, such as the Food and Drug Administration (FDA) and the National Institutes of Health (NIH), pharmaceutical partners, advocacy groups, and individual donors and corporations that support FARA's mission. For example, Ron spent this past year working closely with the Alliance for a Stronger FDA and the National Organization for Rare Diseases to ensure that the FDA has the resources and intelligence it needs to better perform its functions, specifically related to rare diseases, like Friedreich's ataxia. Ron is also the primary liaison with our Board of Directors and many stakeholders – he functions both as Team Owner and Coach.

Felicia DeRosa joined FARA in December 2007 and is FARA's MVP. Felicia's responsibilities have grown and evolved over time to accommodate FARA's needs. Currently, Felicia manages all of our fundraising initiatives, including events organized by individuals and families on behalf of FARA as well as events run by FARA such as Ride Ataxia, the Energy Ball, and individual fundraising such our annual giving program. Felicia also oversees all FARA communications – press releases, e-blasts, web content, brochures, The Advocate, etc. In addition, she manages many of the operational aspects of FARA such as making sure we have proper donor recognition procedures, and event and liability insurance. Honestly, when any of us have a question or need advice, we all go to Felicia.

Kyle Bryant joined FARA in September 2009 to help us raise awareness and funds through his powerful message and the Ride Ataxia program. The Ride Ataxia program continues to grow in number of events, participants, and donations. Kyle administers the Ataxian Athlete Initiative that provides cycling equipment to individuals with FA. As the FARA Ambassador, he makes sure that FARA's message is carried out to as many stakeholders as possible, expanding FARA's video library and social media presence in the process. Kyle is our Motivational and Spiritual Leader.

Jamie Young joined FARA in June 2010 and has proven herself as FARA's Rookie of the Year. Jamie ensures that FARA's donor database is up-to-date and that all donors receive proper recognition and documentation of their gift to FARA. Jamie assists with all our meeting and conference planning, including the logistics for the 4th International FA Scientific Conference in May 2011 – this was no small feat since the meeting was in Strasbourg, France and Jamie's hometown in Illinois did not offer much schooling in the French language. Jamie also led our Team FARA program this year, increasing the number of participants and events. Jamie is the person to greet you when you call or email the FARA office.

Drs. Bronya Keats and Giovanni Manfredi are FARA's Scientific Research Officers. Bronya and Giovanni lead FARA's Scientific Advisory Board, which is responsible for annually evaluating and chartering our research initiatives. This is essentially our research playbook. Our research initiatives tell us the most important things we need to accomplish and where to focus our resources to advance us to treatments. Bronya and Giovanni also lead and/or participate in many of our scientific working groups, such as the cell and animal model groups and the conference planning committee. They oversee our grant program to ensure that we are utilizing our funds for the best quality research. Bronya and Giovanni review all of the grants that FARA receives internally, but also they seek external peer review of all grant applications. Finally, they follow up with FARA-funded scientists to monitor the progress of the research.

Blair DeSaw is FARA's webmaster and designer. Blair helped design the Ride Ataxia and FARA Energy Ball pages. He is on call 24-7 to post the most current information to all FARA sites. In addition, Blair lends his IT skills to other FARA initiatives such as creating a database for FARA scientists to share information about cell models.

So I guess that leaves me… I oversee all of FARA Operations and Research Programs and support fundraising and awareness efforts. The most important part of my job is to coordinate the execution all of FARA's programs (grant program, patient registry, research conferences, fundraising and awareness); In other words, I function as the Team Captain. I am the overall Coordinator for the Collaborative Clinical Research Network in Friedreich's Ataxia – this means that I am responsible for the overall operations of the network and for the strategic direction and relationships to leverage this network as a tool for advancing clinical trials. I work closely with Ron, Bronya, Giovanni, and FARA's Scientific Advisors to support their roles and efforts. I also manage and oversee all FARA's contracts with research institutions – when we fund a research grant we enter into a contract agreement with the scientist and research institution for the funds provided and the work (research) to be performed. In terms of Operations, I am the bookkeeper, human resources manager, and facilities and equipment department (finding donated office furniture).

One core belief through the entire FARA organization is that we are not here to build an organization that stands the test of time and but rather we are a Team focused on victory – treating and curing FA – and going out of business. I am so proud to be a part of this Team.

At the time of this publication I will have participated on behalf of Team FARA in the Philadelphia Half Marathon (November 19) and I hope to have recorded a new personal time record.

Please visit my Team FARA site –
http://curefa.org/farmer.htm ■

mitochondrial degradation resulting from oxidative stress and to augment ATP production in partially dysfunctional mitochondria. In a recently published paper (Arce et al, 2011, A strategy for suppressing redox stress within mitochondria, ACS Med. Chem. Lett. 2:608-613), Dr. Hecht and his colleagues demonstrated that they had developed an MRQ that protects FRDA fibroblasts from oxidative stress more effectively than either Idebenone or Idebenol. They are continuing to develop and evaluate modified MRQ compounds to identify those that are likely to be the most effective therapeutic agents for FRDA.

FARA is also funding the development of clinical management guidelines for FRDA, which will be a valuable resource for assisting clinicians and FRDA patients in making appropriate health care decisions. Additionally, FARA continues to support and expand the Collaborative Clinical Research Network (CCRN) and the standardized characterization of FRDA mouse models at the Jackson Laboratory. Another research area that FARA is supporting is the exciting advances in differentiation of induced pluripotent stem (iPS) cell lines from FRDA patients into sensory neurons and cardiomyocytes. (See the description of Dr. Joseph Sarsero's project below.) As with the mouse models, using standardized protocols to characterize these FRDA iPS cell lines is essential; to this end FARA recently organized a focused meeting of researchers working on the generation and differentiation of FRDA iPS cells to discuss issues and compare results. This meeting, which took place in Philadelphia in October, followed up on items discussed at the FRDA Stem Cell Task Force meeting held directly after the Strasbourg conference in May. An important outcome was the development of the FRDA iPS database, which provides detailed information about all available FRDA iPS cell lines.

Titles and summaries of most of the projects presently funded by FARA are available at: **www.curefa.org/RPMP/public/pggrantlist.aspx** and complete listings of grants awarded by year can be accessed at: **www.curefa.org/grants-awarded.html**

Recently Awarded Named Grants

Phillip Bennett Translational Research Award

Principal Investigator: Dr. Gino Cortopassi, University of California, Davis

Repurposing existing approved drugs for FRDA therapy

Using a novel high-throughput screening assay and a library of 1640 drugs that have already been approved for use in humans, Dr. Cortopassi identified 40 drugs that protect FRDA patient cells from death. The screening assay is based on the sensitivity of FRDA fibroblasts to the thiol oxidant diamide. The goal of this project is to determine the mechanism of action of these protective drugs. Dr. Cortopassi will also examine their relative potency and their efficacy in cell and animal models in preparation for clinical testing in humans. Because these drugs have already been approved by the FDA for other purposes, this "repurposing" approach has substantial potential to reduce the lag time between laboratory testing in cell and animal models and approval of the drug as a treatment for FRDA. Thus, determining the mechanism and efficacy of these drugs is a top priority, because of the potential for rapid translation to FRDA patients.

Kyle Bryant Translational Research Award

Principal Investigator: Dr. Joseph Sarsero, Murdoch Children's Research Institute, Melbourne, Australia

Correction of FRDA iPS cells by non-viral gene therapy

FRDA is an inherited progressive disorder of the nervous system and muscles that results in the inability to coordinate voluntary muscle movements. Improper heart function is also a common and life-threatening condition of the disease. The genetic defect that causes FRDA results in reduced levels of an essential protein termed frataxin in all cells of the body. Stem cell therapy has the potential to repair or replace damaged tissues and restore organ function in individuals with FRDA. Major advances in stem cell technologies have led to the development of 'embryonic-like cells' from adult human tissue. These cells, known as induced-pluripotent stem (iPS) cells, have essentially the same properties as embryonic stem cells, and thus can be used to derive any mature cell type. Prior to the transplantation of nerves or heart cells derived from FRDA iPS cells, it will be necessary to restore frataxin protein to levels compatible with normal cell function. In this project Dr. Sarsero and his collaborator, Dr. Mirella Dottori, propose a means to correct the defect inherent in FRDA iPS cells by a gene therapy approach that will restore normal FRDA gene expression and does not leave any 'genetic scars' in the cells. The strategy addresses major safety concerns for the clinical use of iPS cells and should facilitate compliance with regulatory agency requirements for the approval of the use of these cells in transplantation medicine. ■

2011 Friedreich's Ataxia Treatment Pipeline

By Jennifer Farmer

The Friedreich's Ataxia Treatment Pipeline is a visual way for us to share information about drug discovery, drug development, clinical trials, and overall progress towards treatments. This pipeline is ever-evolving. The more change we see, the better — this means research is moving forward. Bars that move up show progress from the lab bench to studies in patients. Adding new bars demonstrates new discoveries and possible new treatments. Sometimes we will need to remove or replace bars on the pipeline when a drug candidate fails to deliver. While this is disappointing, it is inevitable, and it does not mean that we have not learned valuable information. In fact, when we understand why a drug candidate fails to work or meet expectations, this is incredibly informative and continues to advance and inform our treatment efforts.

FARA supports these pipeline initiatives by:

- *Providing research grants to scientists who are working on lead candidates.*
  - In 2011, FARA has provided the funding for one of the clinical trials, Resveratrol, and provided more than 9 research grants to other projects shown on the pipeline.
- *Promoting collaboration with pharmaceutical partners, academic discovery scientists, and the Collaborative Clinical Research Network in FA.*
- *Advocacy at a national/government level that increases opportunities and resources for individual scientists and pharmaceutical companies advancing treatments for rare diseases and promoting better, expedited regulation of the drug development and approval process.*
- *Providing recruitment support to clinical trials through the FARA Patient Registry.*

Progress in the FA Treatment Pipeline

In 2011 there has been significant progress in the treatment pipeline.

Key Advancements and New Candidates

EPI- A0001 – Edison Pharmaceuticals completed a phase II study of EPI-A0001 and announced initial results in June 2011. EPI-A0001 is alpha-tocopherolquinone, a drug that functions in the mitochondria. The primary endpoint of insulin resistance did not show statistically significant improvement; however, there was significant improvement in neurological function assessed by the Friedreich's Ataxia Rating Scale (FARS). This double-blind placebo-controlled trial included three arms: placebo, low dose, and high dose EPI-A0001. The improvement in the FARS was statistically significant in both the high and low dose groups in comparison to placebo. There were no differences in the rates of drug-related adverse events between the placebo group and each of the drug-treated groups. Another study, which Edison is working to develop and implement, will follow up on these encouraging results.

EPI-743 – Edison Pharmaceuticals is advancing another compound, EPI-743, which aims to improve mitochondrial function by targeting the enzyme NADPH quinone oxidoreductase 1 (NQO1). EPI-743 works to synchronize energy generation in mitochondria by countering cellular redox stress. EPI-743 has been administered to about 60 subjects with inherited respiratory chain diseases (mitochondrial conditions including Friedreich's ataxia) who are at end-of-life or at risk for blindness.

Mitochondrial Radical Quenchers (MRQs) – This is a new bar on our chart. Dr. Sid Hecht at Arizona State University is designing and testing compounds that target the mitochondrial dysfunction that occurs in FA. FARA provided funding to support Dr. Hecht's work to design compounds that will perform multiple functions in mitochondria. These compounds are now being tested in various cell and animal models of FA. Dr. Rob Wilson enthusiastically referred to this approach as "Hecht Wizardry" at a recent FA conference.

Resveratrol – Resveratrol has been under intense investigation as a compound that could improve mitochondrial function and some studies suggest increased longevity, lowering glucose levels and anti-cancer activity. Researchers in Australia found that resveratrol also increased frataxin levels in laboratory studies. Dr. Martin Delatycki designed an early open-label, multi-dose, pilot study to evaluate if resveratrol has an effect on frataxin levels in patients. FARA provided funding for the study, which began enrolling patients in April 2011. They hope to complete the study in early 2012.

OX1 (indole-3-propionic acid) – This is a naturally occurring small molecular weight drug compound that prevents oxidative stress by a combination of hydroxyl radical scavenging activity and metal chelation. This compound was added to our pipeline this year. Originally developed by Intellect Neurosciences for Alzheimer's disease, this drug had advanced through Phase I studies in healthy adults and was found to be safe and well-tolerated. Pharmacokinetics revealed that the drug was rapidly absorbed and distributed in the body after oral administration. A larger pharmaceutical company, ViroPharma, recently purchased the licensing rights of OX1 and plan to advance this drug in Friedreich's ataxia. ViroPharma expects to initiate a phase 2 study within 12 to 18 months after completion of longer term toxicology studies. ViroPharma intends to file for Orphan Drug Designation upon review of the phase 2 proof of concept data.

Epo and Epo-mimetics – Epo and various forms of Epo remain an active area of investigation. One trial of a carbamylated form of EPO, Lu AA24493, was completed early in 2011 by Lundbeck. While they have not released study results, they have publically stated that they are no longer going to continue the program, indicating that the results

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were not positive. Other groups from Austria and Italy continue to report small studies where the safety, dosage, and effect on frataxin continue to be explored. FARA provided a grant this year to a company, Stategics, which is designing and testing Epo-mimetics for FA.

HDAC inhibitors – This group of compounds remains very high on our priority list. RepliGen has a lead candidate, RG2833, which is advancing to human trials. RepliGen plans to get a Phase 1 study initiated in Italy and they continue to conduct pre-clincal and safety studies on this compound in addition to a second HDAC inhibitor, a follow-on compound. The follow-on compound may offer some advantages over RG2833 in terms of metabolic stability and brain penetration.

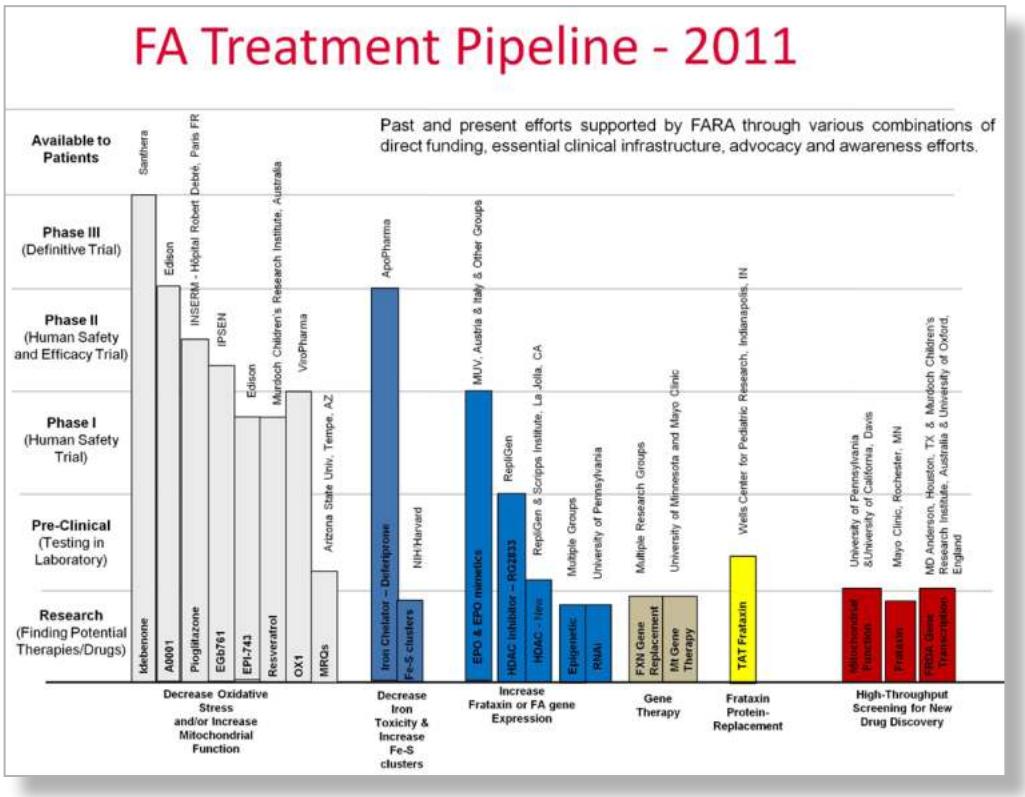
Searching for New Candidates

At the end of the pipeline chart are several red bars that represent research designed to discover new therapeutic candidates. These are primarily high-throughput drug screens. A researcher develops an assay or a test in the laboratory. The assay is specific for function, i.e., improved mitochondrial function, increased expression of frataxin, etc…and is used to screen large libraries of drug or compounds with the goal of identifying "hits."

These "hits" undergo further study to identify new therapeutic candidates that target the mechanism of action or function selected by the assay. Several research groups have developed and validated their assays and completed the high-throughput screening of thousands of drugs and compounds and are in the stages of studying their most compelling "hits." It is anticipated that several of these screens will produce new lead candidates that will show up as bars on this chart in the upcoming months.

This is an abbreviated update and summary of some of the lead candidates. The FA treatment pipeline is updated on a regular basis on the FARA website. There is also a more detailed description of each of the lead candidates and the status. **http://www.curefa.org/pipeline.html**

Your participation is critical! Please ensure that FA patients sign up on FARA's patient registry **(www.curefa.org/registry)** so they can be notified regarding clinical trials for which they appear to be eligible. This website also contains postings and information on clinical research studies. Our drug development partners and clinical research network physicians depend on patient participation in clinical research studies to succeed in their efforts, and they are looking to us for that support. ■



The FA Treatment Pipeline is a visual tool for communicating the progress of research in drug discovery and development on lead therapeutic candidates. The horizontal axis groups the lead candidates based on how they work or the approach to treatment. The vertical axis indicates the stage of the research, or where the candidate is in overall development. The first two stages, research and pre-clinical, take place in the research laboratory, and represent early discovery and development. The stages "Phase 1" through "available to patients" are phases of clinical trials/studies.

Hélène Puccio, PhD

Hélène Puccio, PhD is Research Director at INSERM (Institut National de la Santé et de la Recherche Médicale), and Group Leader at the Institut de Génétique et de Biologie Moléculaire et Cellulaire (IGBMC), a joint research unit of CNRS (Centre National de la Recherche Scientifique), INSERM, and the University of Strasbourg in France. Dr. Puccio's laboratory is dedicated to unraveling the causes and mechanisms of Friedreich's ataxia. She is an internationally renowned scientist whose impressive list of publications speaks to her major contributions to FA research.

How did you first get involved in FA research?

After obtaining a PhD in Genetics from Harvard University, I joined the laboratory of Dr. Michel Koenig in 1998 for my postdoctoral training. Although I knew a little about Friedreich's ataxia prior to 1998 (as I did my masters in 1992 with Prof. Jean-Louis Mandel on another neurodegenerative disorder, X-linked adrenoleukodystrophy), my first involvement with FA research came after joining Michel Koenig's laboratory to develop mouse models for FA and to find the function of frataxin. Very quickly I became fascinated with the different aspect of FA, and I decided to devote my early career to building mouse and cellular models for FA. Since 2000, my laboratory has been dedicated to understanding FA, first the physiopathology (the cellular response that occurs in the disease) and more recently the fundamental role of frataxin in the cell. Both are important to understand in order to find a possible cure for the disease.

FARA is very appreciative of all of your contributions to its mission, including your outstanding research, your willingness to review grant applications, your co-organization and hosting of the highly successful "Fourth International Friedreich's Ataxia Scientific Conference" in Strasbourg last May, and your involvement with the FARA Scientific Advisory Board (SAB). As a member of the SAB, what do you see as the major roles for this advisory group?

While FARA is appreciative of my different contributions, I would like to remind everyone that my contribution to FA is a group contribution. The research contribution of my lab is dependent on my talented graduate students and post-doctoral fellows. Together, we imagine and develop new ideas to try to understand the different facets of the disease. Hosting the 4th International Scientific Conference in Strasbourg was an honor and a pleasure for my whole group. The success of the conference, bringing together over 200 people to share their research and questions about FA, was one of the best rewards of my career.

I am a new member of the Scientific Advisory Board (SAB), therefore I have probably not seen all the facets of our responsibilities. In my opinion, we have two fundamental roles:

1) To review scientific proposals addressed to FARA for funding: our role is to determine if the proposal falls within the scope of the mission of FARA and if the proposal is scientifically sound — that is, if the proposed research has a chance to find an answer to the question being asked.

2) To help FARA fill the research gaps, in areas that would be beneficial to FA, which are not currently being funded. This is our consulting role, which is not always easy to do, as FARA is already very up-to-date on new fields of research in which they should invest. However, the SAB is there also to make sure that new fields of research or new investigators are scientifically founded and will contribute to FA research.

You have been a leader in the development of mouse and cellular models for FA. How have these model systems advanced our understanding of the human disease?

We were one of four different laboratories initially involved in the development of mouse and cellular models. Contrary to all our expectations, mouse models were easier to obtain than cellular models. Michel Koenig and I had the chance to develop the first mouse models with clinical and biochemical signs that were very close to those known for FA patients. Our mouse models, which can reproduce both the neurological and cardiac phenotypes of FA patients, allowed us to determine the process of events that occurs due to a deficiency in frataxin. We now know that the primary event is a deficiency in Fe-S cluster enzymes, which leads to a secondary iron accumulation in the mitochondria and a sensitivity to oxidative stress. Although we have been able to show that Idebenone, an antioxidant, can be cardioprotective in our mouse models, our mouse models are still far from perfect, as they do not mimic FA at the molecular level. We have also developed cellular models, based on a rare point mutation that exists in our community, and these models are very helpful

in understanding the role of frataxin. However, the FA research community is still lacking the proper cellular and mouse models to answer further fundamental questions about the disease and to test novel therapeutic approaches.

What do you consider to be your most important contribution to FA research?

My laboratory has contributed to mouse and cellular models that have brought insight into the pathophysiological events of the disease. In addition, these mouse and cellular models are now being used to test different preclinical therapeutic approaches in many different laboratories around the world. I hope that these models will help to bring different therapeutic approaches to the clinic for the FA community.

What are you currently working on?

My laboratory is currently working on three areas of research:

1) Fundamental questions: What is the biochemical role of frataxin? What happens when frataxin levels are too low?

2) Generation of better models: Can we generate better models for FA using induced pluripotent stem cells? These cells are derived from FA patient cells, and are very close to stem cells from which we should theoretically be able to make neurons and cardiac cells. These carry the same genetic information as FA patients. Are these cells a better model to answer our questions? We do not know yet, but we hope that these cells will be more appropriate.

3) Therapy for FA: We are currently trying a gene therapy approach for FA. This is a very new field of research, and I hope to be able to bring some results to you at the next FA meeting.

How long do you think it will be before there are effective treatments for FA?

This is a hard question to answer, although I think that we have never been so close. FARA has been amazing at bringing scientists and pharmaceuticals companies together to work towards different approaches for therapies. There are now many groups working on therapeutic approaches for FA, from candidate compounds based on what we know about the disease to large scale screenings with unbiased approaches (no preconceived ideas, just looking at what helps FA cells or what increases frataxin levels). The FA community should feel privileged that there are many clinical or preclinical trials ongoing, as there are not many rare diseases that have a similar portfolio. This is extremely positive for finding a therapy or a cure. ■

Autopsy and Tissue Donation Program

Learn more about autopsy and tissue donation for research. FA is a very complex disease that affects spinal cord, nerves, brain, heart, bone, and the insulin-producing cells of the pancreas. Through the Autopsy and Tissue Donation Program, researchers are able to conduct a rapid autopsy and harvest important organs to study, leading to improvements in the diagnosis, treatment, and care of others with FA. Many of our recent breakthroughs are based on research made possible through tissue donations from FA families.

For information and formal enrollment in a research program, contact:

Dr. Arnulf H. Koeppen
VA Medical Center
113 Holland Ave
Albany, N.Y. 12208
Tel. 518-626-6391; 518-626-6377; FAX 518-626-6369;
e-mail: **arnulf.koeppen@va.gov**

Parent Liaison

As a parent who has gone through the tissue donation process, Mary-Lisa offers her compassion and wisdom and helps organize the donation. Studies of her son's organs have played a key role in understanding the effects of the disease on heart and other organs. To learn more, contact:

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e-mail: Rocketmom@att.net; FARA e-mail:
Mary-Lisa.Orth@curefa.org

Athlete Profile: Bill Ramsey

Bill Ramsey graduated from Washington and Lee University and has been employed in the field of finance and accounting, both public and private, his entire career. He currently lives in the rolling hills of the Blue Ridge Mountains in beautiful central Virginia with his wife and their two labs. They have one grown child and two more in college.

I've been handcycling seriously since February 2009. The goal at my first race, the Los Angeles Marathon, was simply to finish, but what a surprise when I placed 14th out of 46! So suddenly I found that I have been blessed with this surprisingly fast combination of upper body strength, good lungs, a strong heart, and not a lot of body mass to drag around the course.

Besides handcycling, I erg (use a stationary rower) with the coach of the national adaptive rowing team, who has never accepted the word "quit." It is the best cross-training I have ever done. I play some tennis when my bum shoulder is cooperative, and during the winter I hit the slopes. My first love is sailing, as I have been doing competitive racing since I was a preteen in dinghies to 40 footers and I've managed to do a lot of blue-water sailing. Unfortunately, as FA has progressed, this has tapered way off.

I have two principal goals as an Ataxian Athlete representing FARA. The first is to demonstrate to other people that a disability doesn't mean you are inactive, and I want to make this point with equal emphasis to the able-bodied and the disabled. Secondly, I want to convey that handcycling greatly enhances my life by improving my physical, mental and emotional health. I race because, like most people, there is enjoyment in doing something well and because the anticipation of the next race is the motivation I need to train. I go regularly, regardless of how I'm feeling or what the weather is. The idea is to put it on the schedule and go.

I'd like to repeat, as I often do, the meaning of sports. This is not an original from me and I don't know who to credit: *the benefit of sports is to build strength physically and mentally, to build character, to make friends, to learn to be a team player, to learn how to be gracious in victory and defeat, and to gain self-confidence for what you have accomplished.* ■

Stay fit, challenge yourself, support FA research… Join Team FARA

Team FARA is made up of people around the globe who participate in endurance events on behalf of the Friedreich's Ataxia Research Alliance (FARA) with the goal of raising awareness and funds for FA research. Past Team FARA members have registered as individuals and groups in local marathons, ½ marathons, triathlons, ironman competitions, bike tours and 5K runs.

For more information on Team FARA:

http://www.curefa.org/teamfara.html or email: info@curefa.org

TEAM FARA Friedreich's Ataxia Research Alliance

Brown and Caldwell Named Partner of the Year

By Felicia DeRosa

In 2006, a young man approached his civil engineering firm with a unique time-off request. He needed two months away to complete what was sure to be a life-changing personal journey. Recognizing the significance of the journey to the young man, the firm not only granted the time-off request, but also pledged their whole-hearted dedication to the effort. The firm was Brown and Caldwell; the young man was Kyle Bryant; and the journey was the first Ride Ataxia.

FARA is pleased to announce Brown and Caldwell as this year's Partner of the Year, not only for enabling the cross country trip of one of their own, but for supporting the journey of an entire community to find treatments and a cure for Friedreich's ataxia.

Since Brown and Caldwell's Sacramento office was first approached by Kyle prior to his first 2007 ride, the company's management and employees have proven themselves year after year to be true partners in the Ride Ataxia effort. The firm has been a long-standing financial sponsor of the effort, and its employees have been committed friends of the cause. Over the past four years, the Team BC cycling group has increased their participation in the ride; this year, they reached a record 20 cyclists. Team BC has fundraised both individually for the ride and as a group, hosting a wine tasting and a poker tournament. Also notable is that Team BC cycled through four days of rain in Ride Ataxia III from Portland to Seattle — a mark of commitment and true partnership. Brown and Caldwell volunteers play a key part of the Ride Ataxia Nor Cal planning committee, helping to file permits with the respective municipalities, stuffing registration packets, securing event supplies, and setting up rest stops the day of the event. Brown and Caldwell also generously hosted the pre-ride reception at the US Cycling Hall of Fame, providing a unique opportunity to celebrate fundraising achievements and enjoy pre-ride camaraderie. Recently, new office locations have joined the effort as well, with the Orlando office fielding a team of riders and volunteers for the Orlando ride. Thank you, Brown and Caldwell, for not only getting behind Kyle's initial cycling journey, but for being a partner in the Ride Ataxia movement; which has funded over $1 million and nine FA research grants — bringing us all closer to treatments and a cure for FA.

FARA Partner of the Year Selection Criteria

- *Leadership and/or employees/constituents within the partner organization directly support FARA's mission and demonstrate a commitment to curing FA faster than thought possible (e.g. fundraising, in-kind contributions, professional services, etc)*
- *Organizational culture that values community, helping others, volunteerism*
- *Commitment to increasing awareness of Friedreich's ataxia or FARA* ■

Team BC meets outside the Sacramento office prior to Ride Ataxia II.

Team BC is all smiles after completing Ride Ataxia III.

AAI Grant Recipients Announced

FARA, in partnership with The FA Project, Catrike, Anna Maria Oyster Bar, and The Melting Pot are pleased to announce the 2011 Ataxian Athlete Initiative (AAI) grant recipients: Bill Ramsey, Tom Trovinger, Mary Vida, and Patrick Cogan.

Part of the mission of Ride Ataxia is to promote active lifestyles by providing adaptive cycling equipment to people affected by Ataxia. The AAI was established to fulfill this mission.
AAI is administered through a competitive grant application process. Applicants submitted an essay summarizing their experience with Ataxia and their efforts to stay active. Individuals then selected the most appropriate adaptive cycling equipment to suit their abilities and described how such equipment would help them to reach their fitness goals. AAI grants are awarded based on the merit of the applications, resources requested, and resources available for funding. For more information, visit **http://rideataxia.org/aai.php**

The AAI started in 2009 when Ride Ataxia provided funding for one trike. The generosity of new partners has enabled AAI to fund a total of seven pieces of adaptive cycling equipment in three years.

A beautiful day and a magnificent setting help create a successful Seaside Stride.

Seaside Stride Goes Statewide (and Beyond…)

By Marilyn Downing

Spring 2010: Karen's two children, Keith and Dylan, had been diagnosed with Friedreich's ataxia (FA) and she desperately felt the need to be proactive. Although she had some initial hesitation, Karen dove in, held her first Seaside Stride, and was uplifted by the support from her local community.

Fast forward 12 months to Spring 2011: Karen, heartened by those same supporters, believes she can do it again! This time, Karen feels the push to think bigger, transforming her walk into the "New Jersey Seaside Stride" and inviting other New Jersey FA families to be involved in organizing and hosting the event. These families brought additional participants (a total of 400+), creative raffle baskets, generous t-shirt sponsors, and even a disc jockey. The combined efforts of the NJ Families proved incredibly powerful on the fundraising front as well — tripling last year's total to raise a total of $40,000 this year!

The result is true success…raising research money and increasing awareness while helping other FA families to network with each other.

Karen's top tips:

- *Use what you know. For example, when you are looking for a site for your event, think about your church and other organizations to which you belong.*
- *Consider what pulls people in. In Karen's community, it was the boardwalk and the ocean view. What a setting for a walk!*
- *Include more families with a personal connection to FA. These families will in turn motivate their network of supporters. Karen used FAPG (Friedreich's Ataxia Parent Group online) to locate families in her region. More than 10 families who attended from the region have a family member with FA.*

Thank you, Karen, for rising to the challenge and then going beyond! ■

This group of invincible moms is fighting for their children's health by participating in the NJ Seaside Stride. L to R: Krissa Lazaropoulos (NJ), Debra Simpson (NY), Debbie Dalton (NJ), Cassie Richard (NY), Joanne Staderman (NY), Cindy Trovinger (MD), Gretchen Anderson (VA), Maureen Sweeny (NJ), Karen O'Brien (NJ), Karen Ryan (NJ), and Debbie Golanec (NY)

Keith O'Brien (center) walks the boardwalk with his buddies.

The FARA Advocate is brought to you by:

Contributors: *Ron Bartek, Kyle Bryant, Felicia DeRosa, Marilyn Downing, Jennifer Farmer, Dr. Bronya Keats, Jamie Young*

Editor: *Karen Smaalders* ***Design/ Layout:*** *Anne Myers*

2011 Friend and Ally Award

by Jamie Young

The FARA Friend and Ally Award is presented to volunteers within the FA community that lend their time, talent, and countless hours in support of FARA's mission to find treatments and cure for FA. All of FARA's "friends" and "allies" help the organization stay lean and efficient while advancing research in the most expedited way possible. The recipients of the 2011 Friend and Ally Award are John Jackson and Crystal Wade for their volunteer work expanding the Ride Ataxia Fundraising Program.

John Jackson – Ride Ataxia National Program Launch

Over the past three years, Ride Ataxia has grown from a single annual event into a nationwide fundraising program. The nationwide program got its start when John Jackson, Joint Venture Partner for Outback Steakhouse – Philadelphia area, approached Kyle Bryant about hosting a one-day ride in the Philadelphia area. That year and every year since then, John has committed his Outback team and resources to organizing and hosting a great ride alongside FARA.

From introducing FARA to key sponsors, offering additional volunteer support, helping manage logistics, fundraising, or providing the best post-ride food the Philadelphia area has ever seen, John, his assistant Charlotte, and their team have been true "friends" and "allies" in the success of the effort. In just three short years, the event doubled in size to raise a total of over $400,000, and it laid the groundwork for Ride Ataxia events in other cities. Thank you, John, for fostering the growth of the Ride Ataxia program and raising critical funds to fight FA!

Crystal Wade – Ride Ataxia Media Design

Growing the Ride Ataxia program from one location to four requires a uniform visual design presence in all locations. Crystal Wade provides the necessary branding for the Ride Ataxia program through her designs of all print materials and event shirts. Crystal's creative design work is evident in the end product materials of each ride, but what the general public cannot see is how quickly she responds to all design and edit requests. Crystal's efficiency really helps the FARA Team keep up with the fast-paced event schedule. Crystal shares not only her creativity with FARA, but also her athleticism. She joined the Team FARA movement by running in the California International Marathon on behalf of Team FARA in 2010. Thank you, Crystal, for using your talent to help raise awareness of FARA, Ride Ataxia, and the effort to treat and cure FA! ■

John Jackson, alongside FARA executive Director Jennifer Farmer, FARA Volunteer Mary Vida, and Ride Ataxia Program Director Kyle Bryant, at the 2011 Ride Ataxia Philadelphia.

Crystal Wade and Kyle Bryant out for a 72-mile ride around Lake Tahoe.

Sign up in the Patient Registry Database for Future Clinical Trials.

www.curefa.org/registry

Goals Versus Purpose

By Kyle Bryant

Roger Crawford, keynote speaker at the Children's Hospital of Philadelphia (CHOP) FA Symposium in October, spoke about his struggles and triumphs growing up and competing in tennis as a disabled athlete in a powerful speech about overcoming obstacles. There was a lot of great wisdom in his talk, but the concept that really struck me was the difference between goals and purpose. Goals allow us to set milestones and measure our progress, while purpose gives it meaning. Getting on a trike or handcycle for the first time and riding two miles is a goal. It is easily measureable; you know when you reach that mark and man, does it feel good. However, this goal is even more meaningful against the backdrop of purpose.

As an FA community, our purpose is to cure FA, and in the mean time our purpose is to support each other and have fun on our way to that finish line. We are a united team with a common goal and that gives us purpose. At Ride Ataxia Philadelphia, we reached many goals. We had 500 riders spread across our four different courses. We raised $140,000 for research including a $16,000 donation from our partners at the Philadelphia area Outback Steakhouse restaurants. Seventeen people with FA rode handcycles and trikes, and set and reached new goals. Tom Trovinger rode his first two miles on the new trike he received through the Ataxian Athlete Initiative and said, "It wasn't great...IT WAS AWESOME!"

Ride Ataxia is a platform that allows all of us to reach goals. Fitness goals, awareness goals, fundraising goals…but it is when we reach those goals in the name of FA research and in the presence of our community that those goals take on even more — they have purpose. ■

Team Chelsea, led by Sandy Lane, celebrates a great day of riding.

Isabel Maugee, with a little help from Anita Carbone, completes the 5-mile route.

Join Ride Ataxia in 2012

March 24, 2012	Dallas, Texas
May 5, 2012	Davis, California
July 2012	Chicago, Illinois
October 7, 2012	Philadelphia, Pennsylvania
November 2012	Orlando, Florida

Avery Zaritsky, Kyle Bryant, and Mary Vida gather with family and friends at the FARA Energy Ball.

Energy Ball Raises Record Amount to Cure FA

By Felicia DeRosa

The tremendously successful 2011 FARA Energy Ball surpassed expectations thanks to the team effort of the dynamic planning committee, generous sponsors, and devoted attendees. This year, the concept of "team" was part of the event experience. The high energy sports theme was conveyed through intricately bedazzled custom sports ball centerpieces, scoreboard screens and sports decorations adorning the ballroom, autographs from sports celebrities, the USF and Tampa Bay Lightning Cheerleaders encouraging the live auction crowd to bid higher, and post-dinner game day snacks such as mini hot dogs, popcorn, and cotton candy. Tod Leiweke, CEO of the Tampa Bay Lightning, served as Honorary Event Chair, and Wendy Ryan, Tampa ABC Action News anchor, was the gracious and energetic emcee. In addition to a four-course dinner catered by A La Carte Event Pavilion and the exciting silent and live auctions, guests enjoyed a rocking performance from the popular band, the Gin Blossoms.

A table setting at the FARA Energy Ball featured a custom-made basketball.

Event week kicked off with an informative *"Cultivating the Cure"* educational symposium. Attendees heard from leading researchers about the latest findings in FA science from discovery to clinical trials. One of the symposium highlights featured a panel of FA patients, including Kyle Bryant, Mary Vida, Natchez Hansen, and Nathan Bell, who provided a personal and honest look at life with FA. The following evening, sponsors tried their hand at poker during the Patron Party catered by Bonefish Grill and Carrabba's Italian Grill. Due to the incredible efforts of the Tampa community, the 2011 FARA Energy Ball raised $1.3 million (gross) in support the mission of FARA and our partners at the USF–Ataxia Research Center. Thank you to all of our generous sponsors:

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Glossary of Terms

Biomarker- A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition.

Collaborative Clinical Research Network- An international network of clinical research centers (9 in the United States; 1 in Canada; 1 in Australia) that work together to advance treatments and clinical care for individuals with Friedreich's ataxia.

Fibroblasts- A fibroblast is the most common type of cell found in connective tissue. Fibroblast cell lines from FA patients are made from skin and used to study FA mechanisms and drug candidates.

Functional Measures- Ways to measure physical function. Examples in FA are the Time 25 Foot Walk and the Pegboard test.

High through-put screening- A method for scientific experimentation especially used in drug discovery. Through this process one can rapidly identify active compounds, antibodies or genes which modulate a particular biomolecular pathway.

Hydroxyl radicals- Hydroxyl radicals (OH) result from certain chemical reactions in the cell. They are highly reactive and cause damage to all types of molecules in the cell. Hydroxyl radicals cannot be removed by enzymatic reaction so they need to be scavenged. Some antioxidants, e.g. vit E have hydroxl radical scavenging activity.

Insulin resistance- A condition in which the body produces insulin but does not use it properly. It was thought to be a possible biomarker for FA.

Metal Chelation- Removal of metal from the cell. This is important in FA as an approach to manage the dysregulation of iron in the mitochondria.

Mitochondria- The energy producing part of the cell.

Oxidative stress- An imbalance between the production of reactive oxygen and a biological system's ability to readily detoxify the reactive intermediates or easily repair the resulting damage.

Pharmacokinetics- The study of how a substance is taken up and distributed throughout the body.

2011 Events	Event Organizer	Location	In Honor of
Northeast			
Play for FA	Kim Bellnier	Hilton, NY	Alec & Colin Brown
Valentine's Ball	Becky Chase	Middleboro, MA	Jade Perry
Comedy Night Fundraiser	Kris Mueller & Debbie Dalton	Freehold, NJ	Keith & Lindsey Dalton
Tiffany's Friends for FARA	Joan Gambill	Bridgewater, MA	Tiffany Gambill
Holly's Hope Golf Tournament	Gary Dempsey	Litchfield, NH	Holly Franz
Cosi Charity Night	Holly Miara	Exton, PA	Dylan & Keith O'Brien
New Jersey Seaside Stride	Karen O'Brien	Seaside Park, NJ	NJ FA Families
Chicken Parm Dinner & Third Annual Walk-a-thon	Dennis Wood	Jonestown, PA	Dennis Wood & FA Families
Outback/ Yorktown Lions Down Under Scramble	Ron Duckstein	Mahopac, NY	FA Families
Bode/ Caruso Walk and Family Day	Mary Caruso	North Branford, CT	Sam & Alex Bode
Fuzzy Buzzy Golf Tournament	Paul Stanieich	Windham, NH	Erin O'Neil
Team Donovan-Jarden Triathlon	Norm & Debra Simpson	Rye, NY	Donovan Simpson
Race for Grace	Katie Hopkins	Bristol, RI	Grace Hopkins & Matt D'Iorio
Fifth Annual Bash in the Backyard	Francine Welsh	Harrisburg, PA	Brendan Welsh
McDonnell Music Festival	David McDonnell	Queensbury, NY	Dylan McDonnell
Goblin Gallop	Adirondack Runners	Glens Falls, NY	Dylan McDonnell
Flatbread's Charity night	Erin O'Neil	Bedford, NH	Erin O'Neil
Outback Luncheon	Simpson, Richard, Golanec Families	White Plains, NY	Donovan Simpson, Albert Richard, & Kaela Golanec
Southeast			
Superbowl Party	Eric Maugee	Orlando, FL	Isabel & Christian Maugee
Globetrotter Golf	Dennis Prescott	Tampa, FL	FA Families
PULL for a Cure- Tampa Clay Shoot	Mike Mezrah	Tampa, FL	FA Families
Doral Cocktail Party	Laurent DeJaham	Doral, FL	Isabel & Christian Maugee
Block Sale Fundraiser	Caroline Maugee	Fort Lauderdale, FL	Isabel & Christian Maugee
Get Fit 4 Charity	Dawn Lambert	Dunedin, FL	Gavin Lambert
Caddy Shack Shootout	Outback Carolinas	Pinehurst, NC	FA Families
Swing Away at FA Wiffle Ball Tournament	Candy Stacks	Cumming, GA	Hannah Stacks
West			
Race 4 Results Rabbit Run	Carrie Laird	Bakersfield, CA	Jerod Laird
Laird Family Outback Dinner	Carrie Laird	Bakersfield, CA	Jerod Laird
Century 21 Golf Tournament	Brian Lamascus	Rancho Cucamonga, CA	Josh Lamascus
Stephanie's Hope Boutique	Sharon & Stephanie Magness	Santa Clarita, CA	Stephanie Magness
Lonestar Benefit Bash	Jerry Russell	Flower Mound, TX	Robbi & Becca Van Schoick
Izzy's Bake Sale	Izzy Penston	Alameda, CA	Zoe Penston
Izzy's Angels Concert	Zoe Penston	Alameda, CA	Zoe Penston
Roman's Outback Luncheon	Susie Esqueda	Tacoma, WA	Roman DiCroce
FA-ITH	Bart & Brenda Rupel; Paul & Susan Konanz	Santa Clara, CA	Matt Rupel & Brianne Konanz
5th Annual Truckee Fundraiser	Neal Lacativo	Truckee, CA	Kyle Bryant
4th Annual Outback Luncheon	Paul Konanz	Rohnert Park, PA	Brianne Konanz
Steak & Ale Reunion	Mark Paul	Dallas, TX	FARA Families
Yard Sale for Research	Jerri Townsend	Bakersfield, CA	Jerri Townsend
Midwest			
Young Family Barnraiser	Becky Young	Saybrook, IL	Emily Young
GCMS Dinner Charity Night	Becky Young	Saybrook, IL	Emily Young
Quarter Madness Fundraiser	Cindy Setzer	Marshall, IL	Cindy Setzer & FA Families
Peters' Hole Out For a Cure	Rick Peters	Peoria, IL	Rick & Todd Peters
Heineken with a Heart	Heineken/ Outback	Chicago, IL	FA Families
FA Woodstock	Paula Hook	LaPorte, IN	Carli Hanson, Kati Hook & FAFamilies
Evan's Quest for a Cure	Tammy Luebbe	Liberty Township, OH	Evan Luebbe
Girls Doing Good FA Fundraiser	Lake Denk	Kansas City, MO	Lake Denk & FA Families
Shone Foto FARA Fundraiser	Megan Marhofer	Howell, MI	Jack DeWitt
CANADA			
FARA Fundraiser Hockey Game	Gabrielle Angiolelli	Quebec	Gabrielle Angiolelli & FA Families
Car Wash for FARA	Shauna Korzenowski	Edmonton, AB	Dallas Gendal

2011 Team FARA Events	Team Captain	Location	In Honor Of
RUNNING			
Emerald Across the Bay 12K	Katie Walsh & Stephanie Hollingsworth	San Francisco, CA	Steve Hollingsworth
Oakland Marathon	Claudia Sieber	Oakland, CA	Sophia Sieber Davis
7 Mile Bridge Run	Dana & Charlie DeFlippo	Florida Keys	Carol DeFlippo
Boston Marathon	Anna Timbie	Boston, MA	Garrett Timbie
See Jane Run 5k	Zoe Penston	Alameda, CA	Izzy Penston
River Run 1/2 Marathon & 5K	Sarah Minko	Cleveland, OH	Anne Cook
Chicago 1/2 Marathon	Jennifer Waterman & Jamie Young	Chicago, IL	Kyle Waterman & Emily Young
ING NYC Marathon	Sally Braid, Lori Pitta, Kris Goldhair, Molly Magee, & Andy Kaynor	NY, NY	Donovan Simpson, Suzanne Staderman Dunstan, & Bill Staderman
Philadelphia 1/2 & Full Marathon	Jen Farmer, Lauren Kowalski, Brian Johnson, Felicia & Allison DeRosa	Philadelphia, PA	Linda Johnson & All FA Families
Athens 1/2 Marathon	Katie Van Schoick	Athens, GA	Robbi & Becca Van Schoick
City to the Sea	Kiersten S Patterson	San Luis Obispo, CA	Stephanie Magness
Chicago Marathon	Doug Fink	Chicago, IL	Carli Hansen & Kati Hook
Carkeek 12 Hour Run	Mike Gore & Molly Billingham	Seattle, WA	Sam Bridgman
HIKING/ CLIMBING			
Adirondack Excursion	Mike DelSignore	Glens Falls, NY	Dylan McDonnell

Thank you to all of our FA families and friends for hosting fundraisers to raise awareness and support research advancement for FA. At the close of October 2011, these volunteers had collectively raised over $700,000 in support of FARA's mission to treat and cure FA.

The Hook family once again hosted FA Woodstock in La Porte, IN, bringing together over 70 people from the FA community.

People had extra inspiration during the workout for the Get Fit 4 Charity night in Dunedin, FL.

Another successful luncheon held at Outback Steakhouse in White Plains, NY hosted by the Golanec, Simpson, and Richard families.

Francine and Eilish Welsh welcoming their community out for another successful Bash in Backyard in Harrisburg, PA.

Young Family hosting the 2nd Barnraisier in Saybrook IL – bringing together a few of the Midwest families from the FA community.

Teams heading out to the course for the Peters' Hole out for a Cure in Peoria Illinois – with over 100 golfers participating.

Team Annie Bananie after completing the River Run Half Marathon and 5K in honor of Anne Cook.

Team Emily completing their second Team FARA event at the Chicago Half Marathon in honor of Emily Young.

In honor of her son Kyle – Jennifer Waterman teamed up with friends and created Team Kyle to participate in the Chicago Half Marathon.

Mary Caruso, Sam and Alex Bode, shown here with CT Congresswoman Rosa DeLaura, hosted a great turn out for their walk and family day in North Branford, CT.

Ron Bartek and Erin O'Neil are all smiles at the annual Fuzzy Buzzy Golf Tournament in Windham, NH.

Heineken with a Heart brought surrounding families together in Chicago, IL for a great night at Outback Steakhouse.

Race for Grace had another amazing turnout in Bristol, RI – raising over $11,000 for FARA.

Team Donovan had another great year at the Jarden Westchester Triathlon in Rye, NY with participants swimming, biking, and running in honor of Donovan Simpson.

Team Stephanie's Hope participated in City to the Sea in San Luis Obispo, CA in honor of Stephanie Magness.

Doug Finck after completing his 7th Marathon in Chicago - in honor of the Hook Family.

Laz Amanatidis, Ron Bartek, Bill Alefantis and Paul Avery pause for a photo in the ballroom at the FARA Energy Ball.

MEMORIALS

From January 2011 to October 2011, FARA has received over $75,000 in memory of the following individuals:

Aaron Kittel, Alberta Marshall Hale, Amanda Hale, Bernard Rundle, Bettie Canaday, Brent Moore, Carol DeFlippo, Christine Ward, Dallas Gendal, David Beeman, Elena Raymond, Frances Rea Grant, Georgia Morton, Glen Lindahl, James Dour, Jean Irvine, Jennifer Alexander, Jim Drakos, John Andresen, John Grant, John Lehto, John Sullivan, Katherine Farmar, Keith Andrus, Lisa Wolf, Mark Peth, Mary Kime, Mary Louise Harrington Hodskins, Merrill Rushin, Michael Policastro, Milton Levy, Nelson Avery, Paul Flippo, Phil Bennett, Phillip Fisher, Richard Flowers, Sue Mullaney, Thomas Barnett, Tyler Hancock, Faye Thomas and Walter Franklin Drake.

Thank you to all who chose to remember a loved one with a donation to FARA.

To request envelopes to be used for memorials, please contact FARA at info@cureFA.org.

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