The eAdvocate

FARA Friedreich's Ataxia Research Alliance

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

Issue #14 Summer 2012

From the Executive Director

Meeting to Help Advance Research Programs

By Jennifer Farmer

The FARA team started off 2012 running and laser-focused and not just because we were participating in running events and clay shoots! We all feel the urgency to get treatments advanced faster and the exciting scientific discoveries and new additions to our pipeline are the fuel.

One of FARA's key activities to help advance scientific knowledge and research projects is planning and attending meetings! Planning meetings takes a lot of work; attending meetings is easier, but you get out of it what you put in and the pay dirt is post-meeting follow-up! While everyone has had the occasional experience of attending unproductive meetings, properly utilized meetings can inform and motivate, address key issues that might be impeding progress, reduce timelines, and lead to new partnerships. Consider the following recent examples…

February 17 and June 13: FA Clinical Development meeting of 8-10 people included four participants from a pharmaceutical company developing a drug for FA, along with two FA researchers and two FA clinicians from the CCRN in FA, and FARA scientific directors and representatives, to discuss preclinical strategy and outline the first patient study of the drug;

March 8-9: Meeting with 70 mitochondrial researchers (academic and industry) at the National Institutes of Health (NIH) to share information related to primary mitochondrial diseases among NIH investigators, survey obstacles, needs and priorities of primary mitochondrial diseases, and develop mechanisms to enhance translation of basic science discoveries to diagnostics and therapeutics.

Continued on p. 3

In this issue:

FARA's Research Grant Program

By Bronya Keats, MD

FARA is presently providing over $2 million in funding for 23 research grants that address drug discovery, advancing lead candidates to clinical trials, gene and stem cell therapies, cell and mouse models, biomarkers and clinical endpoints, and increased understanding of the molecular pathogenesis of Friedreich's Ataxia (FA). Additionally, FARA continues to support the critical work done by the international Collaborative Clinical Research Network (CCRN) in FA to facilitate clinical research and trials. The CCRN in FA is an international network of clinical research centers that work together to advance treatments and clinical care for individuals with Friedreich's Ataxia. For more information, go to **http://curefa.org/network.html**.

Examples of 2012 publications reporting the results of FARA-funded research include a study showing that interferon gamma increases frataxin expression in cell and mouse models of FA and another indicating that DNA mismatch repair proteins protect GAA repeat expansions against instability. Both of these studies suggest new therapeutic approaches that are being actively pursued. Establishing robust biomarkers and clinical endpoints is essential for clinical trials; in this regard, papers evaluating promising new biomarkers such as serum cardiac troponin I levels and DNA methylation profiles have been published in the past few months. In addition, recent publications have

Continued on p. 6

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.

We Need You to Help Us Keep Our Promise

Dear friends,

Most of these letters have been focused on the excitement we all feel about the very promising research and tremendous potential of near-term breakthroughs, especially in the clinical trials currently underway or about to begin. While you will see in this issue of The Advocate plenty of reasons for us to be more excited than ever about the promise of the near-term future, I want to concentrate this letter on what we all can and should do right now to benefit the people living with FA in our lives. In fact, there are several things we need to do right now to accelerate and fulfill that promise, make it happen, and make it happen even faster.

Everything each of us needs to do right now was convincingly brought to light in a meeting in Philadelphia in early June. I wish you could have all been there. A small, new drug company assembled a small team to plan an FA clinical trial they would like to propose to the Food and Drug Administration this Fall. The FA team consisted of two excellent clinicians, Dr. David Lynch and Dr. Susan Perlman of FARA's Collaborative Clinical Research Network in FA (CCRN in FA); two of the finest FA basic scientists, Dr. Rob Wilson and Dr. Mark Payne; and from FARA, Jen Farmer and me.

The drug company's leadership made it clear that there were a number of other neuromuscular disorders they could have selected to test their drug. They chose FA because they knew it has an effective patient advocacy organization that has advanced basic understanding of the disease and provided the infrastructure the company will need to conduct its clinical trial. They were familiar with FARA's patient registry that we use to recruit for clinical trials quickly and effectively, and they also knew about the CCRN in FA clinics, at which hundreds of FA patients are examined each year and much of the FA clinical research is conducted.

The discussion quickly turned to two important aspects of trial planning: 1. How do we apply all we are learning from the CCRN patient exams to design the very best clinical trial, and 2. Will FARA's patient registry be able to adequately recruit multiple clinical trials if several are active at the same time?

What wonderful challenges to face! Most rare disease groups are scrambling to figure out how to collect enough data (natural history) from patient exams to make a difference, and there we were spending a full day designing a clinical trial based on the natural history data being collected in the CCRN. Most rare disease groups are eagerly awaiting the day when they will have a single clinical trial underway, and there we were, telling the drug company that FARA and the FA community will welcome the challenge of recruiting for several simultaneous clinical trials, and that we will meet the challenge!

Jen and I made a lot of promises that day and, as always, we depend on you to do what you need to do right now:

1. Make sure your person living with FA *is enrolled in FARA's patient registry — go to* ***www.curefa.org/registry****, and 2. Get your person living with FA to a CCRN site to be examined, help refine the natural history data, consider participating in any research projects underway there, and otherwise prepare for the upcoming clinical trials. (See page 7 for a complete list of CCRN sites.)*

Yes, Jen and I wish you could have been with us for that exciting meeting. And yes, we made a lot of promises that day because we knew you would help us keep them; you always do.

Warm regards,

Ron

More about Collaborative Clinical Research Network (CCRN):

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

At this meeting, FARA staff met two new pharmaceutical partners, raised awareness about the need for more coordinated efforts on mitochondrial disease research at NIH, and strengthened our partnership with the United Mitochondrial Disease Foundation.

May 18: While I was at the American Society for Human Gene and Cell Therapy meetings, Ron Bartek attended "Patient Input into FDA Benefit-Risk Decision-Making: Opportunities and Challenges," a meeting in Washington, D.C. hosted by the FDA. At this meeting, Ron and many other advocates were able to emphasize the severity of disease, impact on quality of life, and the importance for the FDA to seek patient input early and often in the regulatory review process (pre-IND and IND), as well as when considering market approval.

May 20 and 21: In Philadelphia, a meeting organized by FARA brought FA scientists from around the world who are working on mouse models, induced pluripotent stem cell (iPS) models of FA, and gene therapy approaches. Researchers presented their latest data (not yet published or publically available) to help address gaps in the current models and share new discoveries and technologies. Cat Lutz from JAX labs reported on a significant breakthrough in a collaborative project, funded by FARA, to produce extensive characterization of several different FA mouse models. They identified a reproducible and measurable ataxia (similar to what we see in individuals with FA) in one of the models. This is significant because it gives us an animal model for testing the effects of various drugs on the neurologic phenotype in FA. Several other investigators reported on ongoing efforts to continue to improve upon these models. For example, the current mouse models are still relatively mild compared to humans (symptoms are mild and slow to appear) – if newer models had lower levels of frataxin or more cardiac symptoms, and showed symptoms earlier in life, our ability to screen drug candidates would be enhanced.

Three different research groups presented on unique approaches to gene therapy for FA. Each group is evaluating different approaches of delivery to give individuals with FA a fully functional copy of the frataxin gene. Dr. Helene Puccio shared very encouraging data that showed how she was able to rescue a severe form of cardiomyopathy in an FA mouse with frataxin "knocked-out" in the heart.

May 22: Ten people met at the Texas Heart Institute including five FA scientists and clinicians specializing in the heart and four world-renowned cardiac researchers from other areas of expertise lending their critical feedback, advice, expertise, and new ideas to cardiac challenges in FA.

Since January we have had more than 15 meetings with 10 different biotech/pharmaceutical partners, attended five large meetings bringing together scientists, clinicians, industry, government, and advocacy partners in mitochondrial disease, ataxia, gene therapy, and the rare disease community, and organized and hosted three FA scientific meetings. We continue to see great returns on these very focused meetings that bring together key experts in the same room to talk openly about their work in real time.

In addition, we convened FARA's Scientific Advisory Board to discuss what we learned from these meetings and we continue to evaluate how to:

- *Best utilize FARA resources to facilitate drug development and clinical trials.*
- *Overcome rate-limiting factors in drug development.*
- *Leverage knowledge and resources from other areas of research.*
- *Better understand neurodegeneration in FA so that we can begin thinking about what will happen to individuals once we stop the disease at a cellular level.*

and several other topics that keep me awake at night. Planning, participating in, and following up on the action items from all these meetings definitely keeps the FARA team at a sprint pace through this marathon. More importantly, these meetings facilitate rapid knowledge sharing, keeps our research community in close collaboration, addresses issues early, reduces drug development timelines, identifies new partnerships, and gives all of us a voice to share our urgency and conviction – CURE FA! ■

Viridian Energy Gives to FARA

Viridian Energy offers greener energy while giving back to FARA.

If you live in IL, PA, MD, NJ, NY, CT, or MA, visit www.viridian.com/fara to make Viridian your energy supplier. FARA will receive a $10 bonus and $2 for each additional month of service for new customers.

There are no contracts, no commitments, and you can switch back to your original supplier at anytime.

We Are Not Alone in the Fight For a Cure

By Kyle Bryant

On a warm March morning just outside of Dallas I sat in my trike as cars pulled into the parking lot. The lot was a huge space in front of the new Apogee Stadium at the University of North Texas. Before I knew it, the parking lot was filled with cyclists pouring in to register for the Ride Ataxia event. There were some familiar faces on trikes, and many new faces on bikes, who by the end of the day would become part of the FAmily — the force in the fight for a treatment and a cure.

Team Blazing Dove: Joleen, Phillip, and Patrick Maxwell (Ron's nephews and niece in law) anxiously await the start of Ride Ataxia Dallas.

It was then I realized that we are not alone anymore. People are learning about FA and joining the movement. That day, we had 700 total riders who helped raise $140,000 for research. The largest chunk of that total came from Outback Steakhouse Charity nights at local restaurants. For one night, the managing staff waited tables, endured friendly heckling from regulars, and donated 100% of their tips to FARA. This effort totaled an incredible $95,000! The success of this Dallas ride belongs to the combined efforts of the generous Outbackers and our local FA families.

One month later we held the NorCal ride near Sacramento, CA. Because Sacramento is my hometown, this Ride holds a special place for me. There are a lot of people who have endured the elements and traveled a lot of miles with me — family, friends, and coworkers. The windy conditions did not discourage participation, which reached 350 participants who raised $100,000 for research.

Again I was reminded, I'm not alone, we're not alone, and even more — we're doing amazing things together! The ride program started with three people in 2007 and in 2012 alone we have already reached over 1,000 total participants in just two events, with four events still remaining this year!

We have expanded the program to include two new locations. The first new location will be outside of **Chicago on July 22** following FA Woodstock. The second new location will be near **Portland, OR** on the beautiful **Sauvie Island** on **September 22.**

Returning locations from last year include the Ride outside **Philadelphia, PA on October 7** prior to the Children's Hospital of Philadelphia FA Symposium and the scenic Ride outside **Orlando, FL on November 4.**

We are honored to work with dynamic FAmilies and Outbackers in each location who are the eyes, ears, and power on the ground, making each ride such a success. With each ride, the effort gains momentum, we reach new milestones together, and I'm constantly reminded that we are not alone. We all look forward to reaching the biggest milestone together — treatments and a cure for FA.

For additional details, visit **www.rideataxia.org**. ■

Natalie's Team Hope Riders and Emily Penn finish up a great day of riding at Ride Ataxia Dallas.

Izzy Penston braves the wind to fuel cyclists at a rest stop at Ride Ataxia Nor Cal.

Meet Your NYC Marathon Team FARA

By Jamie Young

"The resilience of people with FA is a daily reminder for me not to take anything for granted in life," says Team FARA member John Lagedrost. John is one of five Team FARA members participating in the 2012 ING New York City Marathon on November 4. Although these five teammates may be separated geographically, they are united with the same goal to Cure FA. Your NYC Marathon Team FARA includes:

Lori Pita – Rye, NY – A Team FARA veteran, this will be Lori's second NYC Marathon for Team FARA, She also participates as a part of Team Donovan in the Jarden Westchester Triathlon. Lori's participation is inspired by the Simpson Family. She identifies similarities between her father's struggles with Multiple Sclerosis and the challenges faced by people living with FA. Lori's goal is to exceed her fundraising effort from last year.

Steve Wisinski – Brighton, MI –Steve joined Team FARA because he wants this race to be different! As an avid runner, Steve usually participates in races for the solitude of a long run with his own thoughts. This year he wanted to take something that he loves and use it to make a difference. Steve is running the NYC Marathon in honor of friend, Jack DeWitt, and he hopes to raise $200 per mile for FARA.

Brian Schutter – Cambridge, MA – Brian joined Team FARA in honor of his high school friend and former cross country running teammate who was diagnosed with FA. The natural link between their shared interest in running and the opportunity to participate in the NYC Marathon on behalf of Team FARA was a natural fit.

John Lagedrost – Chicago, IL – The NYC Marathon will be John's 3rd marathon and Team FARA event in honor of his younger sister, Joanna, who was diagnosed with FA several years ago. John says that his sister is a fighter and a constant source of motivation and inspiration. His hope is that the team's efforts will help spread the word about FA research and ultimately lead to a cure for this disease.

Patrick Hammil – Toronto, Canada – Patrick was unaware FA existed until a year ago, when he began working with a client, Santhera, a pharmaceutical company involved in researching and developing treatments for FA. Upon hearing the stories of determination and empowerment of people living with FA, Patrick was inspired to get involved in the cause.

If you'd like to cheer on Team FARA in the NYC Marathon, please contact Jamie Young at **jamie.young@curefa.org.**

To learn more or join Team FARA with another athletic event, please visit **http://fara.kintera.org/teamfara**. To read more about the Team's journey and other Team FARA participants, go **http://teamfara.blogspot.com/**. ■

Attention all Ataxian Athletes!

Applications for the 2012 Ataxian Athlete Initiative (AAI) are now available! Whether you are an avid adaptive cyclist or a beginner with no experience, this is your opportunity to apply for funding for your adaptive cycling equipment! Download your application at **rideataxia.org/aai.php**.

Application deadline: September 1, 2012.

ATTENTION ALL REGISTRANTS IN THE FARA PATIENT REGISTRY:

WE NEED YOUR INFORMATION!

The FARA Patient Registry is undergoing an upgrade, and there are new data fields in the registry that need to be completed. Please log in to your account to answer these new questions and fulfill this data need for research.

www.cureFA.org/registry

demonstrated the potential usefulness of speech, vision, and auditory measures for FA clinical trials.

A comprehensive list of FARA-funded and other research publications on FA is available at: **http://www.curefa.org/scientific-news.html**

Five Recently Awarded FARA Grants

New Investigator Award: Dr. Vijayendran Chandran
A senior postdoctoral fellow with Dr. Daniel Geschwind at UCLA, Dr Chandran is developing an inducible mouse model of FA such that frataxin levels can be reduced and restored. This model has the potential to complement and extend the capabilities of existing FA mouse models for advancing our understanding of the pathogenesis of FA and the function of frataxin, as well as for testing promising therapeutic agents.

Keith Michael Andrus Memorial Award (for cardiac research): Dr. Francesco Saccà, University Federico II of Naples, Italy
Dr. Saccà, together with Dr. Alessandro Filla, is conducting a phase II clinical trial to test the efficacy of EPO on exercise capacity in patients with FA. In this randomized, double-blind, placebo-controlled trial, EPO is being administered every 12 weeks for a total duration of 48 weeks. As well as exercise capacity, the clinical protocol also includes monitoring of frataxin levels, cardiomyopathy, vascular reactivity, clinical progression, and safety.

EPO project at STATegics Inc., Menlo Park, CA (Principal Investigator: Dr. Juha Punnonen)
This study is evaluating improved EPO mimetics in FA cell and mouse models to follow up on previous findings that these compounds increase frataxin levels. The goal is to identify an optimal therapeutic candidate to advance to clinical trial.

HDACi at Repligen Corporation, Waltham, MA (Principal Investigator: Dr. James Rusche)
This study will complete a thorough evaluation of a follow-on HDACi candidate (RGFP963) to the HDAC inhibitor, RG2833, for which a phase I clinical trial is taking place in Italy. The follow-on candidate has some specific qualities that will likely make it a better clinical candidate, e.g., crossing the blood brain barrier better (better penetration to the nervous system) and metabolic stability.

Therapeutic compound identification by Dr. Marek Napierala (University of Texas MD Anderson Cancer Center, Houston)
Dr. Napierala received funding to characterize potentially therapeutic compounds identified using a high throughput screening (HTS) assay that detects compounds capable of alleviating GAA repeat-induced silencing. Using Dr. Napierala's assay, HTS of 360,000 compounds was carried out through the NIH Molecular Libraries Screening Centers Network; he is now evaluating several promising hits for their effect on frataxin expression in FA fibroblasts and neuronal cells differentiated from induced pluripotent stem cells.

All of these projects (as well as others funded by FARA) are focused on bringing us as rapidly as possible to the time when we have effective treatments for FA. Titles and summaries of most of the projects presently funded by FARA are available at: **www.curefa.org/RPMP/public/pggrantlist.aspx**. Grants awarded by year can be accessed at: **www.curefa.org/grants-awarded.html** ■

Collaborative Clinical Research Network in Friedreich's Ataxia (CCRN)

Children's Hospital of Philadelphia, Philadelphia, PA
Principal Investigator – Dr. David Lynch
Coordinator – Karlla Brigatti
Brigatti@email.chop.edu
Telephone: (267) 426-7538

University of California Los Angeles, Los Angeles, CA
Principal Investigator – Dr. Susan Perlman
Coordinator – Maria Casado
mcasado@mednet.ucla.edu
Telephone: (310) 206- 8153

University of Chicago, Chicago, IL
Principal Investigator – Dr. Christopher Gomez
Coordinator – Vicki Staszak RN, MS/MBA
vstaszak@neurology.bsd.uchicago.edu
Telephone: (773) 702-5545

Emory University, Atlanta, GA
Principal Investigator – Dr. George Wilmot
Coordinator – Rebecca McMurray
rebecca.s.mcmurray@emory.edu
Telephone: (404) 728-6427

University of Florida, Gainesville, FL
Principal Investigators – Drs. Tetsuo Ashizawa and Sub Subramony
Coordinator – Becca Beaulieu, M.S.
Becca.bealieu@Neurology.Ufl.edu
Telephone: (352) 273-9194

University of South Florida, Tampa, FL
Principal Investigator – Dr. Theresa Zesiewicz
Coordinator – Kelly Sullivan, MSPH
kbarber@health.usf.edu
Telephone: (813) 974-5909

University of Iowa, Iowa City, IA
Principal Investigator – Dr. Kathy Matthews
Coordinator – Carrie Stephan, RN
carrie-stephan@uiowa.edu
Telephone: (319) 356- 2673

University of Minnesota, Minneapolis, MN
Principal Investigator – Dr. Khalaf Bushara
Coordinator – Diane Hutter, RN
dhutter@umphysicians.umn.edu
Telephone: (612) 625-2350

Sick Kids, Toronto ON, Canada
Principal Investigator – Dr. Grace Yoon
Telephone: (416) 813-5929

The Bruce Lefroy Centre for Genetic Health Research, Murdoch Children's Research Institute
Melbourne, Austalia
Principal Investigator – Dr. Martin Delatycki
Coordinator – Geneieve Tai
geneieve.tai@mcri.edu.au
Telephone: (613) 8341-6374

Starting Fall 2012
The Ohio State University, Columbus, OH
Principal Investigator – Dr. Subha Raman
Coordinator – Sharon Chelnick
Telephone: (614) 293-4969

ATTENTION ALL REGISTRANTS IN THE FARA PATIENT REGISTRY: WE NEED YOUR INFORMATION!

The FARA Patient Registry is undergoing an upgrade, and there are new data fields in the registry that need to be completed. Please log in to your account to answer these new questions and fulfill this data need for research.

www.cureFA.org/registry

The Difference CCRN Made for Me

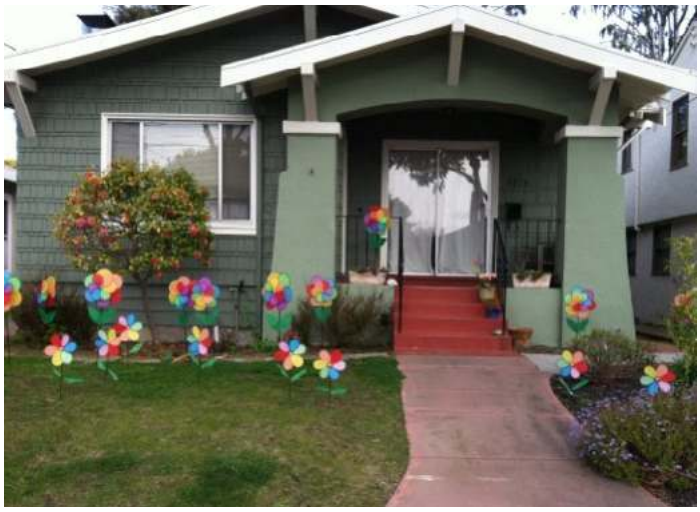
By Erin O'Neil

"There is no treatment, and no cure. We will schedule you for a six-month follow-up. Have a nice day."

This is what I heard from my doctors following my diagnosis in 1992, and year after year it was always the same. When I did go back for my six-month follow-up, the doctor had me balance on one foot in my socks. I did, lost my balance, fell, and sprained my ankle, right in the exam room! I didn't go back.

Two years ago I went and saw a specialist at the Children's Hospital of Philadelphia (CHOP), part of the Collaborative Clinical Research Network in Friedreich's Ataxia (CCRN). We did many neurological exams, which I had done in the past, but this time was different. Dr. David Lynch and his team have seen so many people with FA that I didn't feel as if I had a rare disease. We talked a lot, he listened, and he was so knowledgeable on the issues and quality of my life.

I became part of the research. I had done many fundraisers to raise money for FARA, so this was a great opportunity to do more. Blood draws, mouth swabs, timed tests…visits to Dr. Lynch and his team are encouraging and full of promise. The clinical research is the key to finding a treatment or cure for those of us with FA. I look forward to my annual visit to CHOP and playing an active role in the quest for a cure. Twenty years after my diagnosis, I am still going strong and full of hope. ■



Rainbow flowers in the front yard show who is helping to raise funds for FA.

Flowers Help Share Spirit of Izzy

By Marilyn Downing

After Izzy's diagnosis in the summer of 2010, her family felt a sense of relief. Finally, her doctors knew what was happening and could of course do something to cure her! But then, Izzy found out there was no treatment for this thing called Friedreich's Ataxia. She was told that it takes money to find an answer and her immediate response was, "Well, we should raise money!" Within a month, Izzy set up her first fundraiser—a lemonade stand—and she raised more than $200.

The Penston family, consisting of Izzy, her Mom, Zoe, her Dad, George, and her little brother, Owen, lives in the close-knit community of Alameda, CA, a suburb of San Francisco, and their eager friends finally had a way to help out. Within six months a committee was formed — a very smart and focused committee, according to Zoe Penston, Izzy's mom — and "Izzy's Angels" took wing. Local dads who were part-time musicians performed and many local angels came to enjoy the festivities. Together, the first and second "Izzy's Angels" concerts have raised more than $22,000. Izzy loves the spotlight and enjoys a dance in her wheelchair; her fun-loving attitude sets the mood for the party.

Izzy is adept at making videos and her touching "How to Turn a Cookie into Hope" video is about her annual bake sale. Izzy is determined to fund the science that will help her and others with FA. Her life "is what it is," her mother says, and Izzy just takes each day as it comes, with an upbeat outlook toward her life.

Since April, being "bloomed" in Alameda means you might wake up in the morning with rainbow flowers covering your yard to tell you that you've been nominated to help raise funds for research for FA. Any size donation is gratefully received and then the colorful flowers and sign move on to grace another family's lawn. The flowers have traveled throughout neighborhoods and the research dollars in honor of Izzy have added up.

Izzy's fans cycled as Team Izzy in Ride Ataxia NorCal in May, bringing in $9,500. Again, Izzy was right there with a big smile, handing out refreshments, and ready to put together a video memory of the day.

Check out **www.hopeforizzy.com** where you can see videos of all of the fundraisers the Penston family has held. Izzy gives all of us hope, with her energetic and can-do approach. Thank you, Izzy, from FARA, our scientists and our entire FA community. ■

Izzy and her rainbow flowers.

Izzy and her mother, Zoe Penston, at an FA fundraiser.

UPCOMING EVENTS

July 18 – 21, 2012
FA Woodstock
LaPorte, IN

July 22, 2012
Ride Ataxia Chicago
Channahon, IL

July 24, 2012
Heineken with a Heart –
Outback Fundraiser
Newington, CT

August 10, 2012
Welsh Family Bash in the Backyard
Harrisburg, PA

August 18, 2012
Outback/FARA –
Research Luncheon
Rohnert Park, CA

August 18, 2012
Kickin' For Kids
Plainville, CT

September 6, 2012
Understanding the Cure-
FARA Energy Ball
Educational Symposium
Tampa, FL

September 8, 2012
The 2012 FARA Energy Ball
Tampa, FL

September 8, 2012
Friends of Jerod –
Reverse Draw Dinner
Bakersfield, CA

September 9, 2012
Fuzzy Buzzy Golf Tournament
Windham, NH

September 9, 2012
Team FARA –Team Holly Tripp
Ironman Wisconsin

September 10, 2012
Hole Out for a Cure Golf Tournament
Peoria, IL

September 16, 2012
Team FARA- Rock 'n Roll
1/2 Marathon
Philadelphia, PA

September 20, 2012
Century 21 Golf Tournament
Rancho Cucamonga, CA

September 22, 2012
Ride Ataxia Portland
Sauvie Island, Portland, OR

September 22, 2012
Slim's Journey – FARA Run/
Walk 5K
Warrentown, MO

September 23, 2012
Team Donovan
Jarden Westchester Triathlon
Rye, NY

October 7, 2012
Ride Ataxia Philadelphia
Limerick, PA

October 7, 2012
Team FARA – Vicki Peer
Chicago Marathon
Chicago, IL

October 8, 2012
CHOP FA Symposium
King of Prussia, PA

October 13, 2012
Race for Matt & Grace
Colt State Park, RI

October 13, 2012
The Third Annual Swing Away at FA
Dawsonville, GA

November 4, 2012
Ride Ataxia Orlando
Clermont, FL

November 10, 2012
Stephanie's Hope Holiday Boutique
Santa Clarita, CA

Please check the FARA website for contact information and a full list of events.

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*

THE FARA ENERGY BALL

September 6-8, 2012 in Tampa, Florida.

To benefit FARA and USF Ataxia Research Center

Book your tickets online now.
www.curefa.org/EnergyBall
Donations in lieu of attendance are gratefully accepted.

September 6
Understanding the Cure Scientific Symposium

September 7
Casino Night Patron Party

September 8
The FARA Energy Ball with live performance by The Soul Power Review

Thanks to Our Generous Sponsors

PLATINUM SPONSORS
A La Carte Event Pavilion
clw real estate services group
Jabil
Lightning Foundation
Standard Meat Company
Liz Smith & Chip Newton

BIDPAL UNDERWRITING SPONSOR
Laser Spine Institute

GOLD SPONSORS
Bob and Debbie Basham
Beam Global Spirts and Wine, Inc.
Bill & Charlotte Horne
Vic & Lisa Lafita
Performance Food Group
Southern Wine & Spirits
Chris and Sandi Sullivan
USF Health
John and Martha Zumwalt

As of July 12, 2012

SILVER SPONSORS
Kier & Lauren Cooper
Ron & Peggy Duckstein
Keith & Gaylaine Harvey
Michael & Lori Kosloske
Tampa General Hospital
Trinchero Family Estates
Paul & Avery Zaritsky
Zmithrovith & Rattner Families

TABLE SPONSORS
Academic Alliance in Dermatology
Baldwin Krystyn Sherman Partners
East Lake Pediatrics

MEDIA SPONSORS
Broad Reach Television, Inc.
Clear Channel Outdoor
Tamp Bay Times
Tampa Bay Metro Magazine

Design donated by:
Brand Architecture, Inc.

Printing donated by:
Central Florida Press

Presenting Sponors:

MillerCoors™

Paul and Mary Jacobs

The Avery Family Foundation

BLOOMIN' BRANDS

OUTBACK STEAKHOUSE

CARRABBA'S ITALIAN GRILL

BONEFISH GRILL

Fleming's PRIME STEAKHOUSE & WINE BAR

Roy's

Sophia Sieber-Davis rides in a bike trailer, built by Paul Konanz, at Ride Ataxia Nor Cal.

Susan Piroth enjoyed the happiest place on earth while raising funds and awareness for Team FARA at the Disney World Marathon.

The NJ Seaside Stride takes over the boardwalk at the Jersey shore on FA Awareness Day.

The Seaside Stride FAmily after a walk on the boardwalk and lunch catered by Carrabba's Italian Grill.

Team Bax gets ready to ride for Team FARA in Tour de Palm Springs.

The planning committee for the Race 4 Results/ Rabbit Run in Bakersfield, CA, in honor of Jerod Laird, celebrate another successful event.

Just a few of the over 200 participants at Race 4 Results, raising funds and awareness for FA research.

Lambert Family and friends enjoyed Friedreich's Ataxia Bingo in Palm Harbor, FL on Rare Disease Day.

Many gathered for the Carrabba's instructed cooking lesson at Pull for A Cure, a Sporting Clay tournament in Tampa, FL.

FARA Executive Director Jen Farmer along with Pull for A Cure event host Mike Mezrah congratulate a silent auction winner at the event.

People enjoyed great friends and food at the Spark Hope Cocktail Party in Boston, MA.

Project Adventure participants at play during a day of team building in Beverly, MA.

Pre-jog photo at the St. Catherine's Academy Annual Jog-A-Thon in Anaheim, CA in honor of Chelsea Lane.

Team RTO celebrates at the finish line representing Team FARA at the Reno-Tahoe Odyssey in Reno, NV.

Everyone showed off dance moves at the Drake Family Benefit Dance in Franklin, VA.

Happy FAmily volunteers at the Lone Star Benefit Bash.

Gavin Lambert leads the guys out to course for the Anytime Fitness Golf Tournament.

Team Tri 4 Gracey gets ready in their Team FARA gear for the Golf Coast Triathlon in Long Island, NY.

Contact Us

FARA Friedreich's Ataxia Research Alliance

Friedreich's Ataxia Research Alliance
533 W Uwchlan Ave
Downingtown, PA 19335

Phone: **(484) 879-6160**

E-mail:
info@cureFA.org

Web Site:
www.cureFA.org