



Building Strength and  
Promoting Courage

## Newsletter Winter 2010

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### Table of Contents

<b>2009 Review</b>	<b>1</b>
<i>Helping the FA Community FA Symposium Fuzzy Buzzy Golf</i>	
<b>A Glance at 2010</b>	<b>3</b>
<i>Bowlathon Poker Tournament</i>	
<b>Featured Article</b>	<b>4</b>
<i>FA Fact Sheet</i>	
<b>Make a Difference</b>	<b>5</b>
<i>Donate Volunteer Spread the Word</i>	

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## • 2009 Review

### Helping the FA Community in 2009

To date, The FA Project donated one thousand dollars to FARA, [www.curefa.org](http://www.curefa.org) through the Fuzzy Buzzy Golf Tournament. The donation went to FARA's main objective of advancing scientific discoveries into treatments that improve health and quality of life for people with Friedreich's Ataxia.

We also funded six travel grants to the Second Annual Friedreich's Ataxia Symposium in Philadelphia that took place on November 14, 2009. The Symposium brought together those that are connected to FA and provides up to date clinical information, therapeutic approaches and current research being conducted in the field of FA. The recipients listed below were provided financial aid with travel expenses enabling them to attend the event.

Jade Perry – *College student with FA (spotlight article available online - [http://thefaproject.org/fa\\_story.html](http://thefaproject.org/fa_story.html))*  
Sue Kittel – *mother of two children with FA*  
Mary-Lisa Orth – *mother of twin sons with FA*  
Mary Caruso – *mother of two daughters with FA*  
Elizabeth Lis Curry – *mother of a daughter with FA*  
Karen Smaalders - *mother of a daughter with FA*

A very special thanks goes out to all our supporters who have made it possible for these six individuals to attend the event and for making the FA Project's main objective come to fruition.

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The FA Project is committed towards creating awareness of Friedreich's Ataxia, a life altering disease. We aim to educate the public by increasing the visibility of related information & resources and creating a support system for those afflicted with FA. Ultimately it is our goal to provide those living with FA the tools and resources necessary to lead the best life possible.

The FA Project is a 501(c)(3) Charitable Organization established in Massachusetts. Our goal is to raise awareness and funds to benefit those affected with Friedreich's Ataxia.

## Second Annual Friedreich's Ataxia Symposium

On November 14, 2009, with a jam packed agenda that included informative and inspirational speeches the day's events moved quickly with an opening speech by Dr. David Lynch the driving force behind much of the research happening in the FA community. This was followed by inspirational photographer Rick Guidotti of Positive Exposure. As a photographer he has taken thousands of photographs of people with rare genetic disorders. To learn more about Rick and his remarkable work please visit [www.postiveexposure.org](http://www.postiveexposure.org) and while you are there check out the Friedreich's Ataxia gallery listed under genetic conditions.

The symposium is an important event for the FA community at large. Not only does it give individuals affected with FA a chance to connect with other individuals sharing the same struggles it also allows parents and caregivers of those with FA an opportunity to connect to a supportive and informed community. In addition, The Friedreich's Ataxia program at The Children's Hospital of Philadelphia coordinates an agenda that provides participants with information that is relevant and informative. It provides a sense of empowerment and renewed sense of hope for everyone connected to Friedreich's Ataxia.

An exciting new edition to the symposium highlighted 4 young adults living with FA and how it has impacted their careers and subsequently their lives. The panelists spoke with such candor and confidence despite the many obstacles they have faced throughout their lives. The FA Project's inspiration Richie Currier continued to inspire us as one of the speakers featured on the career panel. Richie discussed how FA has impacted his life and major decisions such as attending college and dealing with potential employers.

### FA Project's First Inaugural Summer Gala a Huge Success!



On June 20, 2009, The FA Project hosted its First Inaugural Summer Party at The Stadium Bar & Grill in South Boston, MA. With entertainment provided by Felix Brown, [www.felixbrown.com](http://www.felixbrown.com), and over 160 people in attendance, we were able to gather our group of supporters for a meet and greet and was able to introduce the team's mission while enjoying some cocktails and dancing. The event

raised over six thousand dollars which provided us with a great starting foundation. Again we'd like to thank all who attended and look forward to hosting these same events for years to come.

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## The FA Project Sponsors FARA's Fuzzy Buzzy Golf Fundraiser

The FA Project donated one thousand dollars to the Friedreich's Ataxia Research Alliance (FARA) through a platinum sponsorship of the Fuzzy Buzzy Golf Tournament. On September 13, 2009 in Windham, NH, a few team members and friends joined Erin O'Neil, the inspiration for this event, and others for a fun filled day on the golf course. Our team scored an impressive eight shots under par and attended a post dinner where The FA Project was recognized for its donation. We look forward to attending this event in the future and collaborating efforts to raise awareness and funds through other FA events with Erin and her family.

### • A Glance at 2010

#### "Striking Courage" Bowlathon

The FA Project is proud to announce an upcoming fundraiser scheduled to take place in on Saturday April 10th, 2010. The fundraiser will consist of a night of candlepin bowling alongside over 40 professional bowlers from the local circuit (don't be nervous, it's all in the name of fun). Over 150 participants of all skill levels will participate in Candlepin Bowling with complimentary catered food, beverages and a cash bar. All proceeds will go towards The FA Project's 2010 assistance goals for those affected with Friedreich's Ataxia. No matter whether you throw a Strike, Spare or even a gutter ball, you'll be helping to Strike Courage for those dealing with FA! Tickets can be purchased in advance via our website. Please join us on Saturday, April 10th from 7:00 - 11:00 PM at Candlewood Lanes located at 35 Main St in Norwood, MA 01864.



#### "A Full House of Support" Poker Tournament



The FA Project is putting on its poker face! The Full House for Support poker tournament will take place in May 2010. The tournament will consist of approximately 150 players of all skill levels. Prizes will be awarded to the top winners with the proceeds going to The FA Project and its 2010 assistance goals for those dealing with Friedreich's Ataxia.

The evening will be filled Kings, Queens, and the occasional Joker enjoying catered food, beverages and a lot of action. Those who are ousted from the tournament early can enjoy other various card games while the remaining contenders battle for the pot. Whether you have a Royal Flush or are simply bluffing, your efforts will be sure to assist those dealing with FA to live a better life. That's sure to be the safest bet in the house! If interested in participating in any of these events, please contact Evan Rozantes at [evan@thefaproject.org](mailto:evan@thefaproject.org).

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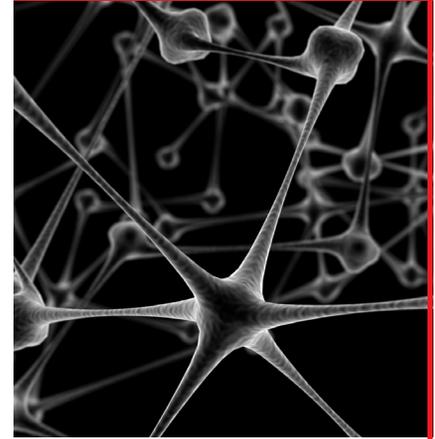


## Friedreich's Ataxia Fact Sheet

By the National Institute of Neurological Disorders & Stroke  
www.ninds.nih.gov

### **What is Friedreich's Ataxia?**

**F**riedreich's ataxia is an inherited disease that causes progressive damage to the nervous system resulting in symptoms ranging from gait disturbance and speech problems to heart disease. It is named after the physician Nicholaus Friedreich, who first described the condition in the 1860s. "Ataxia," which refers to coordination problems such as clumsy or awkward movements and unsteadiness, occurs in many different diseases and conditions. The ataxia of Friedreich's ataxia results from the degeneration of nerve tissue in the spinal cord and of nerves that control muscle movement in the arms and legs. The spinal cord becomes thinner and nerve cells lose some of their myelin sheath — the insular covering on all nerve cells that helps conduct nerve impulses.



Friedreich's ataxia, although rare, is the most prevalent inherited ataxia, affecting about 1 in every 50,000 people in the United States. Males and females are affected equally.

### **How is Friedreich's ataxia inherited?**

**F**riedreich's ataxia is an autosomal recessive disease, which means the patient must inherit two affected genes, one from each parent, for the disease to develop. A person who has only one abnormal copy of a gene for a recessive genetic disease such as Friedreich's ataxia is called a carrier. A carrier will not develop the disease but could pass the affected gene on to his or her children. If both parents are carriers of the Friedreich's ataxia gene, their children will have a 1 in 4 chance of having the disease and a 1 in 2 chance of inheriting one abnormal gene that they, in turn, could pass on to their children. About one in 90 Americans of European ancestry carries one affected gene.

### **Can Friedreich's ataxia be cured or treated?**

**A**s with many degenerative diseases of the nervous system, there is currently no cure or effective treatment for Friedreich's ataxia. However, many of the symptoms and accompanying complications can be treated to help patients maintain optimal functioning as long as possible. Diabetes, if present, can be treated with diet and medications such as insulin, and some of the heart problems can be treated with

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medication as well. Orthopedic problems such as foot deformities and scoliosis can be treated with braces or surgery. Physical therapy may prolong use of the arms and legs. Scientists hope that recent advances in understanding the genetics of Friedreich's ataxia may lead to breakthroughs in treatment.

### ***What research is being done?***

**W**ithin the Federal government the National Institute of Neurological Disorders and Stroke (NINDS), a component of the National Institutes of Health (NIH), has primary responsibility for sponsoring research on neurological disorders. As part of this mission, the NINDS conducts research on Friedreich's ataxia and other forms of inherited ataxias at its facilities at the NIH and supports additional studies at medical centers throughout the United States.

Researchers are optimistic that they will soon be closer to understanding the causes of the disease, which eventually will help scientists develop effective treatments and prevention strategies for Friedreich's ataxia.

## • **Make a Difference**



### **Help us help others!**

Here are a few ways you can assist The FA Project in supporting those in need:

#### **Donate**

Make a donation at  
[www.thefaproject.org](http://www.thefaproject.org)

#### **Volunteer**

Volunteer by contacting  
[evan@theFAproject.org](mailto:evan@theFAproject.org)

#### **Spread the Word**

Tell a friend what you've learned about FA...your voice is important and every friend of The FA Project helps!

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