



Building Strength and Promoting Courage



• Recent Events

## Newsletter Fall 2009

### The FA Project Team Members

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

On June 20, 2009, The FA Project hosted its 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 raise \$6,000. We'd like to thank all who attended and give a very special thanks to all our supporters

for providing us with a foundation to achieve our main goal of helping those affected with FA.

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

With funds raised to date, The FA Project donated \$1,000 to the Friedreich's Ataxia Research Alliance known as FARA through a platinum sponsorship of the Fuzzy Buzzy Golf Tournament. On September 13th in Windham, NH, a few team members and friends joined Erin O'Neil, the inspiration for this event, and a hundred other participants for a fun filled day on the golf course. The FA Project team scored an impressive eight shots under par and attended a post dinner where The FA Project was recognized for its donation. The team looks forward to attending this event in the future and collaborating efforts to raise awareness through other FA events with Erin and her family.

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.

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## “Striking Courage” Bowlathon

The FA Project is proud to announce an upcoming fundraiser scheduled to take place in March 2010. The fundraiser will consist of a night of bowling alongside over 40 professional bowlers from the local circuit. Over 100 participants of all skill levels will participate in Candlepin Bowling with catered food and beverages. 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!



## “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 April 2010. The tournament will consist of approx 100 tournament 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 with 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).

## Helping the FA Community through Donations

To date, The FA Project donated to FARA [www.curefa.org](http://www.curefa.org) through the Fuzzy Buzzy Golf Tournament, see above. The donation will go 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 have also recently funded six travel grants to this year’s Second Annual Friedreich’s Ataxia Symposium in Philadelphia taking place on November 14, 2009.

The Symposium brings 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

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recipients listed below have been provided financial aid with travel expenses so they are able to attend this year's event.

*Jade Perry – 19 year old college student with FA (Mass.)*

*Sue Kittel – mother of two children with FA (Colorado)*

*Mary-Lisa Orth – mother of twin sons with FA (Arizona)*

*Mary Caruso – mother of two daughters with FA (Conn.)*

*Elizabeth Lis Curry – mother of a child with FA (Michigan)*

*Karen Smaalders – mother of 16 year daughter with FA (Wash.)*

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.

## The FA Project Publishes it's New Website!

Early October marked a new beginning for The FA Project with the launch of its updated website. Designed by SCAD graduate student, Jen Fidler, the new look introduces a brand new logo along with several new pages and features. In addition to learning more about upcoming FA Project events, visitors can follow our live Twitter feed, link to our blog, apply for support, or read about those we've helped!

Visit the new site at [www.thefaproject.org](http://www.thefaproject.org)!



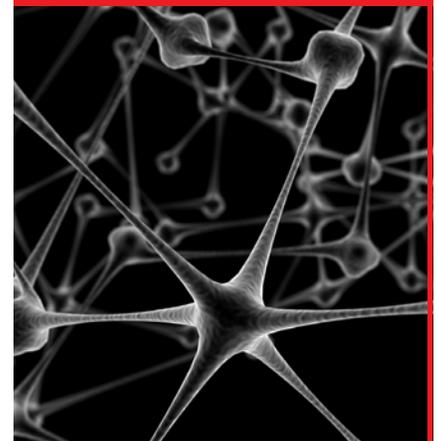
### • Featured Article

## Friedreich's Ataxia Fact Sheet

By the National Institute of Neurological Disorders & Stroke  
[www.ninds.nih.gov](http://www.ninds.nih.gov)

### What is Friedreich's Ataxia?

Friedreich'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.



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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 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.

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## ● **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!

#### **Photo Credits**

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by Gerard79 ([www.sxc.hu](http://www.sxc.hu))  
Page 4 - *Wealth* by Sufi Nawaz

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