

## FARA Progress

### Rapidly Advancing Research

FARA advances FA research by providing competitive grants to leading scientists worldwide to identify scientific and medical discoveries and translate them into treatments. Proof of progress and success is that clinical trials for new therapies are now beginning. We have reached the clinical era in research.

FARA assembles the necessary resources through grassroots fundraising, individual and corporate donors, foundations and by partnering with government, pharmaceutical companies, and other advocacy organizations around the world. We will find a cure!

### Worldwide Partners

- Muscular Dystrophy Association (MDA)
- Ataxia UK
- GoFAR (Italian advocacy group)
- Friedreich's Ataxia Research Association of Australia/New Zealand
- National Ataxia Foundation (NAF)
- Friedreich's Ataxia Society of Ireland
- Friedreich's Ataxia Association of France
- Spanish Ataxia Federation (FEDAES)
- EuroAtaxia
- FA Parents Group (FAPG)
- International Network of Ataxia Friends (INTERNAF)
- FA-babel Family

### Government Sponsors

- NIH Office of Rare Diseases
- NIH National Institute of Neurological Disorders and Stroke (NINDS)

**Connecting public, private and scientific communities to drive medical advances in FA & other neurodegenerative diseases**



FARA International Scientific Conference in 2006

## Ways to Get Involved

FARA's research program would not be successful without the support of grassroots fundraising, individual and corporate donors and foundations. As you consider ways to get involved, please consider an investment in finding a cure.

- Local Fundraisers
- Individual and Corporate Donations
- Stock Donations
- Planned Giving
- Corporate Matching Programs
- In-Kind Gifts
- Memorials
- And more...

**For more information call  
1 (703) 426-1576**

Email  
**fara@cureFA.org**



## Overview & Patient Registry Information

**Resources for Patients,  
their Families,  
Doctors & Clinics**

**“Together, we will find a cure.”**

**Ron Bartek  
FARA President**

**Friedreich's Ataxia Research Alliance  
P.O. Box 1537  
Springfield, VA 22151  
www.cureFA.org**

## Who is FARA

The Friedreich's Ataxia Research Alliance (FARA) serves as a catalyst among the public, private, scientific and patient-family communities, to build worldwide support and collaborations that drive medical and research advances for Friedreich's ataxia.

FARA was founded by a group of parents and patients wanting to make a difference. Through gaining government support, incorporating as a charity and creating a worldwide network of scientists and patients, FARA has grown to be a leading, recognized force in FA research.

**Founded:** 1998

**Country:** USA

**Status:** 501(c)(3) non-profit organization

**Focus:** A research alliance that drives treatments and a cure for Friedreich's ataxia (FA)

**Tax ID No:** 52-2122720

## What is Friedreich's Ataxia

Friedreich's ataxia (FA) is a rare, genetic, neuro-degenerative, multi-system, life-shortening disorder. About 1 in 50,000 people in the United States have Friedreich's ataxia.

Onset of symptoms is usually between the ages of 5 and 15. However, some patients are diagnosed with late onset FA.

## Common Symptoms

- Loss of coordination (ataxia) and muscle weakness in the arms and legs leading to a wheelchair
- Vision impairment, hearing loss, and slurred speech
- Aggressive scoliosis (curvature of the spine)
- Serious heart condition (cardiomyopathy)
- Diabetes or carbohydrate intolerance
- Excessive fatigue, severely reduced energy due to dying nerve and muscle cells
- Difficulty with breathing and swallowing
- All mental abilities remain intact

**Today there is no treatment or cure.**

## Making a Difference

It's hard to know where to begin when first hearing a diagnosis. Sometimes, taking action makes you feel like you're doing something to make a difference. Below are suggestions:

- Learn more about Friedreich's ataxia and FARA on our website [www.cureFA.org](http://www.cureFA.org) and sign-up there for news and email updates.
- Sign up on the Patient Registry if you have been diagnosed with FA.
- FA parents can seek support and advice from an established online parent's group. [www.fortnet.org/fapg/](http://www.fortnet.org/fapg/)
- Attend annual NAF (National Ataxia Foundation) conferences each March for presentations from ataxia specialists and to meet other families. [www.ataxia.org](http://www.ataxia.org)

## Patient Registry Database

Treatments and cures are on the horizon. To ensure we reach the finish line, clinical trials are required to monitor and measure success.

The FARA Patient Registry is our most important tool for helping researchers reach the patient community and recruit patients for clinical trials. The difference between a successful trial and those that are not, is usually sufficient patient participants.

**Please register today!**

## Patient Registry Sign Up

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

### Patient Participation is Simple:

- Go to the FARA Patient Registry website. [www.cureFA.org/registry](http://www.cureFA.org/registry)
- Select the **New Registrant** button at the top of the screen.
- Walk through instruction steps online.



FARA extends a special thank you to EDS volunteers from Rochester, N.Y. and the Rochester Institute of Technology (RIT) who have donated their time and talents to create and maintain our online patient database and other valuable tools that support FA research.