

# PROFILE



## FARA FACTS

<b>Founded:</b>	1998
<b>Country:</b>	USA
<b>Status:</b>	501(c)(3) non-profit organization
<b>Focus:</b>	A research alliance that drives treatments and a cure for Friedreich's Ataxia (FA)
<b>Tax ID No:</b>	52-2122720

## Management and Officers

**Ron Bartek**, Co-Founder and President

**Raychel Furr Bartek**, Co-Founder and Executive Assistant

**Terrence Downing**, Treasurer

**Marilyn Downing**, Secretary and Grassroots Fundraising

**Jennifer Farmer, MS, CGC**, Executive Director

**Felicia DeRosa, MPA**, Executive Assistant/ Program Manager

## FARA Operations

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## Board of Directors

Ronald J. Bartek  
Marilyn Downing  
Terrence Downing  
Paul Avery  
John Cubbin  
Thomas A. DeCotiis  
Nicholas A. Johnson  
Laura Kalick  
Paul Marcotte  
Edward Ramsey  
Nancy Schneid

Dr. Earl Giller, Scientific Director  
Dr. Bronya J. B. Keats, Scientific Director  
Dr. Bernard Ravina, Scientific Director

## Description

The Friedreich's Ataxia Research Alliance (FARA) is a 501(c)(3) organization formed to speed scientific research to find a cure for Friedreich's Ataxia. FARA grants and activities provide support for clinical trials, research grants, workshops and pharmaceutical/ biotech development. FARA also serves as a catalyst, between the public and scientific community, to create worldwide exchanges of information that drive medical advances.

## What is Friedreich's Ataxia?

Friedreich's Ataxia is debilitating, life-shortening, degenerative neuro-muscular disorder. About 1 in 50,000 people in the United States have Friedreich's Ataxia. Onset of symptoms can vary from childhood to adulthood. Childhood onset of FA is usually between the ages of 5 and 15 and tends to be associated with a more rapid progression. Late onset FA (LOFA) can occur anytime during adulthood.

Symptoms can include:

- Loss of coordination (ataxia) in the arms and legs
- Fatigue-energy deprivation and muscle loss
- Vision impairment, hearing loss, and slurred speech
- Aggressive scoliosis (curvature of the spine)
- Diabetes mellitus (insulin dependent)
- Serious heart condition (enlarged heart- hypertrophic cardiomyopathy)

The progressive loss of coordination and muscle strength leads to motor incapacitation and the full-time use of a wheelchair. There is currently no treatment or cure.

## Research Ripple Effect Across Multiple Diseases

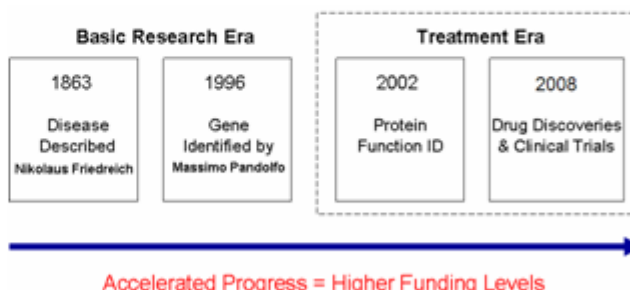
Scientific and medical advances realized by FARA could have a powerful, beneficial impact on the entire medical community for related mitochondrial dysfunction diseases and others like:

- MDA Diseases (ALS, SMA and others)
- Fragile X Syndrome
- Lebers Hereditary Optic Atrophy
- MELAS and MERF
- Stroke
- Parkinson's
- Huntington's
- Alzheimer's
- Diabetes

## From Gene Discovery to Drug Discovery

Since 1998, FARA has successfully:

- Reached clinical trial status in just 7 years of operation.
- Gained Food and Drug Administration (FDA) orphan drug status and NIH support for EPI-A0001 in less than 2 years following drug discovery.
- Lined up 6 promising drugs trial in near horizon (12 months).



## Funding History

FARA has funded over \$9 M in scientific research since 1998

- \$5 M in Research Grants (University, Hospital, etc.)
- \$4.5 M in Biotech Research and Drug Development
- \$500 K in supporting network of clinics
- Three International Friedreich's Ataxia Scientific Conferences

## Funding Requirements

- 2008 - \$3M
- 2009 - \$5M

## Partner Organizations

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

## Government Sponsors

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

## Ways to Support FARA

- Multi or Single Year Donation
- Corporate Donation
- Event Sponsorship
- Project Sponsorship
- Stock Donations
- Planned Giving
- Corporate Employee Matching Programs
- In-Kind Gifts
- Joint Marketing
- Or another creative way!

Contact us to learn more [info@cureFA.org](mailto:info@cureFA.org).



## FARA Faces



Chelsea Lane



Samantha and Alexandria Bode with  
Mary Stuart Masterson



Evan Luebke and Tiki Barber of the  
NY Giants

*"Together, we will find a cure."*  
Ron Bartek  
FARA President