

PROFILE



FARA FACTS

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

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

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Board of Directors

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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

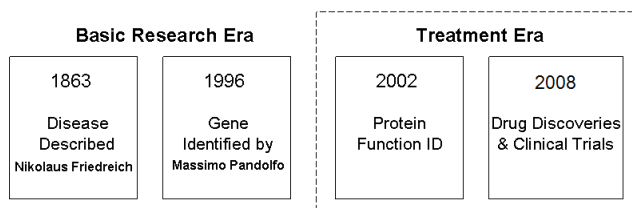
Scientific and medical advances realized by FARA could have a powerful, beneficial impact on the entire medical community for related mitochondrial dysfunction diseases and others like:

- 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.
- Helped move potential therapies into clinical trials



Accelerated Progress = Higher Funding Levels

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.



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