

FARA FACTS

About FARA

The Friedreich's Ataxia Research Alliance (FARA) is a national, public, 501(c)(3), non-profit, tax-exempt organization dedicated to curing Friedreich's ataxia (FA) through research. FARA grants and activities provide support for basic and translational FA research, pharmaceutical/ biotech drug development, clinical trials, and scientific conferences. FARA also serves as a catalyst, between the public and scientific community, to create worldwide exchanges of information that drive medical advances.

FARA was founded in September 1998 by a group of patient families and three of the world's leading FA scientists — Drs. Rob Wilson, Bronya Keats, and Massimo Pandolfo.

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

Tax ID #: 52-2122720

www.cureFA.org

Locations:

FARA Main Office

533 W. Uwchlan Ave
Downingtown, PA 19335

Phone: (484) 879-6160

Fax: (484) 879-1402

Email: info@cureFA.org

FARA President's Office

P.O. Box 1537
Springfield, VA 22151



FARA Staff

Ron Bartek

Co-Founder and President

Jennifer Farmer, MS, CGC

Executive Director

Jane Larkindale

Vice President—Research and Development

Giovanni Manfredi, MD, PhD

Chief Scientific Officer

Bronya Keats, PhD

Chief Scientific Officer

Raychel Furr Bartek

Co-Founder and Patient- Family Liaison

Felicia DeRosa, MPA

Fundraising & Communications Program Director

Kyle Bryant, Founder, Ride Ataxia

Ride Ataxia Director, FARA Spokesperson

Jamie Young

Team FARA and Ride Ataxia Event Coordinator

Evelyn Wu

Communications & Patient Affairs Officer

Ann Musheno

Grassroots Event Coordinator

Erin Goerss

Administrative Assistant & Gifts Processor

FARA FACTS *continued*

Mission

FARA's Mission is to marshal and focus the resources and relationships needed to cure FA by raising funds for research, promoting public awareness, and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to treating and curing FA.

Strategy

FARA focuses on grant making for FA research and building collaborations with organizations dedicated to advancing treatments for FA. Due to the progressive nature of the disease and the promise of treatments in development, there is real urgency to our efforts. Directing attention and resources to FA research and partnering with others that share this commitment, FARA believes it can help bring forward effective treatments and a cure for FA.

FARA's Approach to Treatment

Thanks to the committed efforts of many FA scientists, we now understand the cause of FA and specific mechanisms leading to damage in patients, such as the gene mutation, decreased frataxin production, iron sulfur cluster formation, and mitochondrial dysfunction. FARA is supporting the development of treatments aimed at each of these different mechanisms of damage. Because it is based on solid basic science discovery, this targeted approach to treatment has great potential. Furthermore, FA researchers believe that treatment will come in the form of a “cocktail” therapy - meaning that therapies aimed at the different mechanisms of damage have the potential to be used in conjunction with one another to treat the disorder.



Above, Dr. Grazia Isaya and Zac Zies at The Mayo Clinic, Rochester. FARA has funded Dr. Isaya's seminal work on the function of frataxin, the protein that is deficient in FA patients. Dr. Isaya also inspired FARA to begin work on newborn screening for FA. Future newborn screening will allow patients to be treated before the symptoms of FA appear.

FARA FACTS *continued*

FARA's Activities

- Raise funds for advancing research in FA.
- Develop awareness for FA within the general public, scientific and medical professions and the pharmaceutical industry.
- Facilitate a competitive and highly regarded grant making program that supports greater than \$4 million dollars in research, annually.
- Promote the collaborative exchange of information within the scientific community through conferences and networks.
- Manage an FA patient registry that provides researchers with critical patient data and expedites patient recruitment for clinical trials.
- Support the development of a collaborative clinical network that facilitates clinical trials and provides patients with the highest level of clinical care.
- Foster public-private partnerships with the active participation of academic research investigators, government agencies, pharmaceutical companies, advocacy organizations, patients and patient families.
- Rally patients, patient families, scientific investigators, healthcare providers, pharmaceutical companies, government entities and other non-profit organizations to be supporters and advocates for scientific advancements that will lead to treatments and a cure.



Above, Kyle Bryant and several members of the Ride Ataxia III team that rode 191 miles in four days from Portland, Oregon to Seattle, Washington. Ride Ataxia has become the marquee fundraising event for FARA.

FARA Leadership

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Retired U.S. Government Official; Business Consultant
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CEO, Avery Management Group
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Teacher/ Diagnostician, Special Education, retired
- **Ruth DeWitt, Treasurer**
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Broken Plate Group, Founding Member
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Section Head of Genetics, University of Oklahoma College of Medicine
Department of Pediatrics
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President and CEO, Trevi Therapeutics
- **Thomas Hamilton, Director**
President and CEO, Construction Forms, Inc.
CEO of Esser-Werke GmbH & Co KG
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Associate & Senior Mechanical Engineer,
Bard, Rao + Athanas Consulting Engineers, LLC, retired
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Senior Vice President and Associate General Counsel, Regulatory &
Policy, Pfizer
- **Dr. James McArthur, Director**
Chief Scientific Officer, Cydan Development Inc.
- **Tony Plohoros, Director**
Principal, 6 Degrees PR
- **Edward Ramsey, Director**
Co-Owner and Vice President, Taylor Ramsey Corporation-Retired
Vice President, BEPCO - Timber and Land Development Company
- **Dr. Bernard Ravina, Scientific Director**
VP of Clinical Development, Voyager Therapeutics, Inc.
- **Pat Ritschel, Director**

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Professor, Weill Cornell Medical College
- **Dr. Bronya Keats**
Chief Scientific Officer, FARA
Professor, Australian National University

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Section Head of Genetics, University of Oklahoma
College of Medicine Department of Pediatrics
- **Dr. Grazia Isaya**
Professor of Biochemistry/Molecular Biology and
Pediatrics, Mayo Clinic Rochester
- **Dr. Arnulf Koeppen**
Professor of Neurology and Pathology
Albany Medical College
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Institute of Genetics & Molecular & Cellular
Biology
- **Dr. Bernard Ravina**
VP of Clinical Development, Voyager
Therapeutics, Inc.
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Sr. Vice President Research and Development,
Repligen Corporation
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Physician Executive, Board Certified in Psychiatry
& Neurology, PhD in Pharmacology
- **Dr. Robert Wilson, PhD**
Associate Professor of Pathology and Laboratory
Medicine, University of Pennsylvania