Press & Media Kit

Friedreich's Ataxia Research Alliance (FARA)

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FARA Friedreich's Ataxia Research Alliance

About FARA

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. It was staffed and managed as an all-volunteer organization until late 2005.

FARA's leadership and numerous patient families and friends have raised critical funds over the years to support FA research. Thanks to the brilliant and committed efforts of many FA scientists, we now understand the cause of FA and specific mechanisms leading to damage in people with FA. These understandings allow for more targeted approaches to treatment which are currently being developed for clinical trials.

Our 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 curing FA and related diseases.

About Friedreich's Ataxia

Friedreich's ataxia (FA) is a genetic, progressive neuromuscular disease. People with FA experience issues with balance and coordination of movement that leads to life-altering loss of mobility. Other common symptoms can include fatigue, serious heart conditions, scoliosis, and diabetes. FA is life-shortening and affects an estimated 5,000 individuals in the United States and 15,000 worldwide.

Our Executive Team

Ron Bartek, President

Ron and his wife Raychel are FARA's co-founders, and Ron has always served as FARA's President. While with FARA, Ron has also served as a Director and Chair of the Board of the National Organization for Rare Disorders; past President and current member of the Board of the Alliance for a Stronger FDA; co-founder and Chair of the Board of the National Center for Advancing Translational Sciences (NCATS) Alliance; former Board member of the Alliance for Regenerative Medicine; a 4-year member of the NIH/NCATS National Advisory Council and Co-Chair of the NCATS Cures Acceleration Network Review Board; a 4-year member of the National Advisory Council of the NIH Institute of Neurological Disorders and Stroke, and is a former member of the FDA/CTTI Patient Engagement Collaborative He was recognized by the FDA Office of Orphan Product Development as "one of 30 Heroes changing lives of rare disease patients."

Prior to co-founding FARA, Ron was a partner and president of a government affairs firm. After serving for twenty years in the federal executive and legislative branches in defense, foreign policy and intelligence (six years on the House Armed Services Committee staff; four years at the U.S. State Department, one year on the U.S. Delegation to the Intermediate-Range Nuclear Forces Treaty negotiations with the Soviet Union in Geneva, Switzerland, and six years as a CIA analyst). After graduating from the U.S. Military Academy, West Point, N.Y., Ron served for four years as an Army officer– as a company commander in Korea and the U.S., and as an Infantry and Military Intelligence officer in Vietnam. Ron holds a Master of Arts degree in Russian Area Studies from Georgetown University.

Jennifer Farmer, MS, CEO

Jennifer Farmer is the Chief Executive Officer of the Friedreich's Ataxia Research Alliance. Jennifer has a Master's degree in Genetic Counseling and prior to joining FARA she worked at the University of Pennsylvania and Children's Hospital of Philadelphia. As a genetic counselor, Jennifer developed a special interest in neurogenetic conditions and then went on to establish and coordinate clinical and research programs for individuals and families diagnosed with Friedreich Ataxia (FA) and other neurodegenerative diseases. Having established relationships with the families who founded FARA and sharing in their vision to treat and cure FA she joined the organization full time in 2006. Jennifer has led FARA's efforts to establish clinical research infrastructure and clinical trial readiness, grown the research grant program from funding <1M annually to >9M annually, led efforts to engage bio-pharma industry in FA drug discovery and development, and ensured highly efficient and transparent organizational growth and development. In her current role at FARA as CEO, she helps to carry out the strategic mission of the organization through leading FARA's research and partnership initiatives.

rideATAXIA

rideATAXIA is a nation-wide program of bike rides that welcomes people of all abilities to ride, and to raise funds for FARA's mission to treat and cure FA through research.

History

Initiated by Kyle Bryant in 2007, rideATAXIA has raised invaluable awareness for FA and **over $10 million in support of FA research grants**. Bryant's inspiration spurs from his diagnosis at age 17 and the discovery that he could travel long distances under his own power on a recumbent tricycle. Fueled by the passion to do more for himself and the FA community, Bryant and his family completed a 2,500-mile bike ride from San Diego to Memphis to raise awareness and funds for FA research.

That was just the beginning of rideATAXIA. Now functioning as a program of the Friedreich's Ataxia Research Alliance (FARA), rideATAXIA offers challenging and family-fun bike rides. From all corners of the world, people gather to rideATAXIA events for friendship, camaraderie, and the opportunity to engage new communities, moving forward together towards treatments and a cure.

Director & Founder

Kyle Bryant

Kyle graduated from the University of California at Davis with a degree in Civil Engineering. He worked for 5 years as an engineer before finding his calling through cycling and spreading empowerment to others. As the founder/director of rideATAXIA, Kyle and his team produce family-friendly bike rides across the country to empower those with FA and raise funds for research. Kyle is also the director of FARA's Ambassador Program which welcomes people who live with FA and are 16 or older to learn to represent the community when needed.
Kyle's favorite place to be is on his Catrike and he is probably on the road or bike trail at this very moment.

FA Fact Sheet

Symptoms of FA

All people with FA experience **ataxia**, loss of coordinated movement of the limbs. **Sensory neuropathy** — loss of sensation in the arms and legs — also contributes to the progressive loss of mobility and coordinated movement seen in FA.

Many people with FA also have heart conditions, including **cardiomyopathy** (thickening of the heart muscle) and sometimes **cardiac arrhythmias** (irregular heart rhythm).

Other symptoms of FA include

- Fatigue
- Diabetes
- Dysarthria (slurring of speech)
- Dysphagia (difficulty swallowing)
- Scoliosis
- Vision and hearing loss

FA can be diagnosed at any age, but most people are diagnosed between the ages of 5 and 15 years.

FA is caused by mutations in the **FXN** gene, which encodes the **frataxin** protein.

FA is inherited in a **recessive** pattern. Parents of someone with FA are carriers and do not have symptoms.

Frataxin is a mitochondrial protein that helps generate cellular energy. Lack of frataxin leads to poor energy production and cellular damage.

Treatments

There is one approved treatment for FA, with many more being researched.

SKYCLARYS™ is currently the only approved treatment for Friedreich's ataxia in people aged 16 and older in the US and EU. There are also several potential treatments being investigated on the Drug Development Pipeline. Additionally, the FA Clinical Management Guidelines describe different general medications, interventions, and physical therapy available to healthcare providers for people with FA.

FA Etiquette Guide

FARA Friedreich's Ataxia Research Alliance

Talk to the person with FA, not the caregiver.

It can make a person with FA feel like you do not care about their story if you only talk to their caregiver. Do not ask the caregiver questions about the person with FA — no one can tell it better than the one experiencing it.

The person with FA may defer a question to their caregiver but do not stop giving them a chance to speak.

Don't rush the person with FA while they are speaking.

People with FA usually have slurred or slowed speech. It can be frustrating for them if someone tries to rush their speaking or finish their sentence for them. You may think you're being helpful, but it may come off as inconsiderate. Be patient and make an effort to wait until the person with FA finishes speaking before you begin talking again.

Saying "walk" to a wheelchair user is okay.

There is no need to feel awkward saying "walk." It is not offensive. Most wheelchair users will not even bat an eye. It is more awkward if you are stumbling through a sentence trying to figure out what to say. Go ahead and say "we're going to walk into this room" — no one will think anything of it.

Don't touch a mobility aid without asking.

Whether it's a wheelchair, scooter, walker, or cane, mobility aids are an extension of the person using them. If moving to another room, do not push a wheelchair user without asking if they would like help. If someone sets their cane off to the side, do not move it without asking if it's okay with them.

Just say "disabled."

"Disabled" is not offensive, nor is it a bad word. Just say it. Avoid words like "handicapped," "physically challenged," or "differently abled." There is no reason to tiptoe around the word disabled."

The most important thing to remember is people with FA are just people.