



# PRESS RELEASE

FOR IMMEDIATE RELEASE

## **Friedreich's Ataxia Awareness Day is Saturday, May 19th- Meet a Few of the Faces of Friedreich's Ataxia**

Saturday, May 19, 2012 is Friedreich's Ataxia Awareness Day, a day dedicated to sharing the stories of those enduring the little-known disease and raising awareness and research funds for a cure.

Friedreich's Ataxia (FA) is a life-shortening debilitating degenerative neuromuscular disorder typically affecting children and young adults. Often, signs and symptoms – which worsen over time – include loss of coordination (ataxia) in the arms and legs, fatigue, muscle loss, vision impairment, hearing loss, slurred speech, and heart complications. FA affects roughly 15,000 people worldwide, and, despite international research efforts, there is no known treatment or cure.

This Friedrich's Ataxia Awareness Day, the Friedreich's Ataxia Research Alliance (FARA), a non-profit organization dedicated to funding research to find a cure for FA, is sharing the stories of just a few of the brave individuals battling the disease in an effort to encourage the support needed to continue life-saving research.

**Natalie Newman, 13 years old:** When Natalie was 7 years old her parents just thought she was a little clumsier than most kids her age. But within years, Natalie's condition worsened, and a very different diagnosis was reached. In 2009, a doctor identified hypertrophic cardiomyopathy which is a heart disease affecting the muscle of the heart. Then in 2010, an eye doctor discovered her eyes were offset, meaning Natalie saw the world lopsided. Not long after, it was found that her cardiac enzymes were elevated, which usually is a sign of heart attack in adults. A pediatric neurosurgeon confirmed that all of Natalie's symptoms were consistent with Friedreich's ataxia.

Today Natalie is not only fighting for a cure for herself, but she is fighting for everyone who is battling FA. Natalie and her family have raised over \$25,000 for FARA's research efforts. This combined with her mantra, "If He leads me to it, He will get me through it," has given Natalie empowering strength and determination.

**Izzy Penston, 11 years old:** At 5 years old, Izzy Penston couldn't keep up with other kids. Her handwriting got more muddled with each day. She had an MRI which showed a lipoma; a fatty tumor on the base of her spinal cord which was thought to be the root of these issues. She underwent a surgery to remove the tumor, but the problems persisted. At age 8, Izzy developed a heart murmur and visited a cardiologist who diagnosed her with Friedreich's ataxia.

The same week Izzy was diagnosed with FA, the Penston's learned of a nationwide bike ride, Ride Ataxia, which helps raise funds for a cure. To help with this mission, Izzy had a bake sale in her front yard and

raised \$280. Last year, Izzy and her family collectively helped raise over \$25,000 for FARA through fundraising events.

**Kyle Bryant, 30 years old:** Kyle Bryant was diagnosed at age 17. He was told his abilities would deteriorate over time, would soon be in a wheelchair, would lose the ability to take care of himself, and would likely die a premature death due to heart failure. After Bryant graduated from the University of California at Davis in 2005, he wanted to help fight for a cure for FA. He found he could travel long distances under his own power on a recumbent tricycle. In 2007, 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 the beginning of Ride Ataxia.

After becoming a full-time employee of FARA, Bryant created a ride program that spans the country. Ride Ataxia cycling events have raised invaluable awareness for FA and funded over \$1 million in FA research grants in just five short years.

In honor of FA Awareness Day, FARA is hosting a gene therapy meeting of leading researchers around the world to explore new approaches to treating FA at the root cause of the disease. Members of the FA community are also hosting two fundraising events to benefit such research efforts- a 5k walk in Seaside Heights, New Jersey called the **New Jersey Seaside Stride** and a dinner dance in Wakefield, Massachusetts called **Rockin for a Cure**. To find out how you can help raise awareness about FA on Friedreich's Ataxia Awareness Day (and year-round), 'like' FARA on Facebook: [facebook.com/CureFA](https://facebook.com/CureFA), follow FARA on Twitter: [twitter.com/curefa\\_org](https://twitter.com/curefa_org), or visit [www.CureFA.org](http://www.CureFA.org).

#### **About FA**

The first symptoms of FA are loss of balance and coordination leading to wheelchair use 6-8 years after onset. Additional symptoms include life-shortening cardiomyopathy and arrhythmias, scoliosis, diabetes, and diminished vision, hearing and speech. There are currently no effective treatments. In >95% of individuals with FA there is a mutation in the first intron of the FA gene that decreases transcription of the gene and subsequent production of the frataxin protein.

#### **About FARA**

FARA is a (501)(c)(3) non-profit organization that supports scientific medical research, a clinical network, patient registry, education and awareness. FARA serves as a catalyst among the patient, scientific, pharmaceutical and government communities to create worldwide exchanges of information that drive medical advances to bring treatments and a cure to individuals with FA. [www.CureFA.org](http://www.CureFA.org)

#### **Contact:**

Felicia DeRosar  
Program Manager, Friedreich's Ataxia Research Alliance  
(484) 879 6160  
[info@curefa.org](mailto:info@curefa.org)