



## Press Release

### Cyclist with Rare Neuromuscular Disorder to Begin Third Cycling Journey

#### Announcement

**January 5, 2009** - Kyle Bryant and Team Ride Ataxia are preparing to begin their third cycling journey to draw attention and raise research funds to find a cure for the rare neuromuscular disorder Friedreich's ataxia (FA) with which Bryant and other teammates are affected.

The team will begin the ride on March 16, 2009 at Oregon Health Sciences University in Portland, Oregon and conclude in Seattle, Washington on March 19, 2009 at the National Ataxia Foundation's 52nd Annual Meeting. It will be a 4-day trip covering 200 miles.

Bryant and Team Ride Ataxia have cycled 3,100 miles cross country in the past two years. In 2007, Bryant and his father, Mike Bryant completed a 2,400 mile bike ride visiting FA researchers and patient families from La Jolla, California to Memphis, Tennessee. In March 2008, the Bryants were joined by many new teammates including 6 ataxians on their bike ride from Sacramento, California to Las Vegas, Nevada. The funds raised by the team on their cross-country "Ride Ataxia" have gone directly to the annual Kyle Bryant Research Award for translational research in FA. In 2008, the team raised \$142,000 and the National Ataxia Foundation and the Friedreich's Ataxia Research Alliance added sufficient funds to bring the award total to \$250,000.

[Ride Ataxia](#), [NAF](#) and [FARA](#) co-funded two \$125,000 awards in 2008. One award was made to Repligen Corporation, Waltham MA, which in collaboration with an international team of researchers is advancing compounds called HDAC inhibitors that target increased levels of frataxin - the protein that is severely reduced in FA. The second award went to a team of investigators at Ohio State University, Drs. Subha V. Raman and Roula al-Dahhak, who propose a series of sophisticated imaging studies to better understand, prevent and treat heart disease in FA.

NAF Executive Director Michael Parent commented, "NAF is excited to again partner with Kyle Bryant, Team Ride Ataxia and FARA for the third annual cycling journey. NAF applauds Kyle and Team Ride Ataxia for their continued efforts to support vital Friedreich's ataxia research and enhance ataxia awareness. NAF looks forward to collaborating again this year with FARA to help accelerate important translational research in FA. "

FARA President Ron Bartek added, "Kyle Bryant, his family and his Ride Ataxia teammates are real difference makers. These courageous, resourceful and dedicated people have made their cycles into

vehicles of change that have vastly expanded the horizons of awareness regarding Friedreich's ataxia and have significantly increased financial support for Friedreich's ataxia research. FARA is deeply grateful to Kyle and Team Ride Ataxia and looks forward to the 2009 Team Ride Ataxia/FARA/NAF collaboration that will once again focus increased awareness and resources on the research that will result in treatments and a cure."

Team Ride Ataxia has set a goal of raising \$100,000 towards research for Friedreich's ataxia in 2009. The team is seeking cyclists to join them on their journey as well as sponsors. For information about participation or to make a donation please visit [www.rideataxia.org](http://www.rideataxia.org). Participant applications and deposits are due February 15.

Bryant stated, "In 2009 Ride Ataxia looks forward to continued success raising awareness, collaboratively funding research, and empowering ataxians and others to seek their fitness goals and have fun doing it."

Friedreich's ataxia (FA) is a debilitating, life-shortening, degenerative neuro-muscular disorder. Onset of symptoms can vary from childhood to adulthood and can include muscle weakness and loss of coordination in the arms and legs; impairment of vision, hearing and speech; aggressive scoliosis (curvature of the spine); diabetes, and a serious heart condition. The progressive loss of coordination and muscle strength leads to motor incapacitation and the full-time use of a wheelchair. Childhood onset of FA is usually between the ages of 5 and 15 and tends to be associated with a more rapid progression. There is currently no treatment or cure.

#### **About FARA**

The Friedreich's Ataxia Research Alliance (FARA) is a 501(c)(3), non-profit, charitable organization dedicated to accelerating research leading to treatments and a cure for Friedreich's ataxia.

<http://www.curefa.org>

#### **About NAF**

NAF is a membership supported, nonprofit organization established in 1957 to help persons with ataxia and their families. The Foundation's primary purpose is to support promising ataxia research and to provide vital programs and services for ataxia families. <http://www.ataxia.org>

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