

rid ataxia



## PRESS RELEASE

### FOR IMMEDIATE RELEASE

#### **\$360,000 in Kyle Bryant Translational Research Awards Announced Today**

October 13, 2009 — The National Ataxia Foundation (NAF) and the Friedreich's Ataxia Research Alliance (FARA) announced today that, this year, they are co-funding two \$120,000 Kyle Bryant Awards that are going to promising translational research in Friedreich's Ataxia (FA). A third award will be funded by FARA for \$120,000, made possible by sponsorship from Outback Steakhouse. One award is being made to Dr. Mark Payne of Indiana University School of Medicine, proposal titled "Optimizing delivery of frataxin using cell penetrant peptides". The second award goes to Dr. Gino Cortopassi of the University of California Davis, proposal titled "Screening for mitofunctional Friedreich's Ataxia therapeutics". The third will be granted to Dr. Marek Napierala from the University of Texas, MD Anderson Cancer Center, proposal titled "Crosstalk between microRNAs and iron metabolism in pathogenesis of Friedreich's ataxia".

Dr. Payne's research moves forward efforts toward an approach to frataxin protein replacement, specifically, this grant will support determining the best molecule and optimizing conditions for expression and purification of the protein his group is developing, called TAT-Frataxin to move forward into preclinical development. Dr. Cortopassi's grant allows him to utilize a recently developed assay to screen thousands of compounds for their positive effect on mitochondrial function compromised by deficiencies of frataxin, the protein that is dramatically reduced in individuals with Friedreich's ataxia. Dr. Napierala's proposal aims to identify a biomarker that might be helpful in evaluating the effectiveness of therapeutic approaches by studying microRNAs, molecules that regulate the activity of genes. He hopes to reveal how abnormalities in microRNAs affect the activity of genes which are responsible for the localization and amount of iron in neuronal cells of patients with Friedreich's ataxia and uncover the pattern of detectable microRNA molecules that is specific to FRDA, essentially a "microRNA signature".

These three research projects were selected from fourteen excellent applications that were peer-reviewed and then ranked by FARA and NAF scientific advisors. The Kyle Bryant Translational Research Award was established in honor of Kyle Bryant, the courageous

young man who has Friedreich's ataxia and formed Ride Ataxia. Ride Ataxia has helped increase awareness regarding FA and raise invaluable research funds for FA research. The Ride allows motivated individuals to experience and advance the fight against this debilitating disease. In 2009, Ride Ataxia III began in Portland, OR and ended in Seattle, WA at the 52nd NAF annual membership meeting. Bryant and Ride Ataxia III teams raised over \$260,000 to support the award. NAF and FARA announced at the end of the ride that the two organizations would add sufficient funds to bring the total of the 2009 Kyle Bryant Translational Research Award to \$360,000.

FARA Executive Director, Jennifer Farmer added, "The Kyle Bryant Translational Research award is significant because it demonstrates the full collaboration and participation that is essential from the patient, research, and advocacy communities to treat Friedreich's ataxia. We are most grateful to all of the participants and supporters of Ride Ataxia who raised funds and to all of the researchers who submitted applications for this award." NAF Executive Director Michael Parent commented, "NAF is excited to partner again this year with Ride Ataxia and FARA in supporting vital and promising Friedreich's ataxia research through the Kyle Bryant Translational Research Award. We are truly grateful to all the Ride Ataxia participants, organizers, donors, and sponsors of this event in their efforts to help increase ataxia awareness and support promising Friedreich's ataxia research."

Ride Ataxia III, launched in Portland, OR on March 16, 2009 with nearly 70 riders, including 6 ataxians. Bryant states, "The third ride was the toughest and most successful so far. We look forward to future challenges as we push the limits and advance research."

Bryant and Ride Ataxia are expanding their efforts to cover both coasts in the coming year, with their first east coast ride on October 25 outside of Philadelphia, Ride Ataxia Northern California on May 15-16, 2010, and Ride Ataxia Southern California in November 2010.

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>

#### **About Ride Ataxia**

The mission of Ride Ataxia is to Educate the public about ataxia by drawing attention

through acts of physical endurance, Enable the advancement of ataxia research through collaborative financial support, and Empower ataxians by inspiring, motivating, and providing opportunities to develop physical and mental strength.

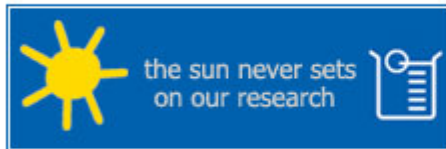
<http://www.rideataxia.org>

### **Contact**

Jennifer Farmer  
Executive Director, Friedreich's Ataxia Research Alliance  
(484) 875-3015  
[info@curefa.org](mailto:info@curefa.org)

Michael Parent  
Executive Director, National Ataxia Foundation  
(763) 553-0020  
[mike@ataxia.org](mailto:mike@ataxia.org)

Kyle Bryant  
Founder, Ride Ataxia  
(916) 203-3238  
[kyle@rideataxia.org](mailto:kyle@rideataxia.org)



[www.CureFA.org](http://www.CureFA.org)