



PRESS RELEASE

FOR IMMEDIATE RELEASE

Mayor of the City of Tampa Proclaims September 25- Ataxia Awareness Day

September 24, 2009- Ataxia advocacy groups and communities around the world are preparing for the upcoming International Ataxia Awareness Day on September 25 with events to increase public awareness about ataxia and raise funds to support research into treatments for the disease. City of Tampa Mayor, Pam Iorio, recognized this important day by issuing a proclamation to declare Ataxia Awareness Day in the City of Tampa, Florida and encouraging Tampa citizens to support people with ataxia. Click to view the [full proclamation](#).

Other events scheduled across the US during the weekend following Awareness Day on September 25 include a music festival in Queensbury, NY; an outdoor party in Martinez, California; and team participation in the Jarden Triathlon in Rye, NY. These events are being held to raise awareness and funds for a specific type of ataxia called Friedreich's ataxia, with proceeds going to the Friedrich's Ataxia Research Alliance (FARA).

Kyle Bryant, Founder of Ride Ataxia and spokesperson for FARA will be appearing on Daytime on Monday September 28th, 2009. Kyle is battling Friedreich's ataxia and he has been a spokesperson and inspiration for many individuals living with ataxia. Click here for [viewing information](#).

Friedreich's ataxia (FA) is a degenerative, neuromuscular disease that gradually robs patients of their ability to walk, compromises speech, hearing, and vision, and often comes with complications of serious diabetes and heart disease. Following the identification of the Friedreich's ataxia gene in 1996, research scientists have learned a great deal about the disorder. We now know what defects in the gene cause the disease, what protein the gene is supposed to produce, what that protein is supposed to accomplish, and why a shortage of the protein results in the cell death that leads to the disease symptoms. With this knowledge, researchers are better equipped to focus treatment development at the causes of the disease with the aim to slow, stop and reverse the effects of Friedreich's ataxia.

Although there is currently no effective treatment or cure available, Friedreich's ataxia patients and families have more and more reason for real hope. This growing optimism is based on the fact there are six clinical trials in progress around the world. One treatment approach under investigation at the University of South Florida and the Children's Hospital of Philadelphia is a study to evaluate whether Varenicline (Chantix®) improves neurological symptoms, such as balance, coordination, and sensory perception, all of

which are significantly impaired in patients with FA. This drug was originally reported to help balance in a few individuals with other types of ataxia.

"While there are distinct differences among these types of ataxia there is commonality in the symptoms of these diseases which brings the patient, medical and research communities together in fighting ataxia. Capitalizing on these similarities, sharing the collective knowledge of the research, and working together to raise awareness everyday is essential to finding treatments and improving the lives of those effected by ataxia" says Jennifer Farmer, Executive Director for the Friedreich's Ataxia Research Alliance (FARA).

Researchers and patient advocates from around the world are convening for International Scientific Ataxia Conference in Valladolid, Spain on September 25th and 26th 2009 hosted by the Spanish Ataxia Federation (FEDAES) and the European Federation of Hereditary Ataxias (euro-ATAXIA).

For more information on Friedreich's ataxia and the Friedreich's Ataxia Research Alliance, please visit www.CureFA.org

About FARA

The Friedreich's Ataxia Research Alliance's (FARA) 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. www.CureFA.org

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