



PRESS RELEASE

FOR IMMEDIATE RELEASE

Research Progress Fuels Preparations for "Friedreich's Ataxia Awareness Day" — May 16, 2009

May 11, 2009, Washington, D.C. — Friedreich's ataxia patients, families, and their communities eagerly welcome the approach of "Friedreich's Ataxia Awareness Day" on May 16th. The third Saturday of May is recognized in Congressional and state proclamations and various activities across the country as "Friedreich's Ataxia Awareness Day." 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 three clinical trials in progress: Idebenone, Deferiprone and A-0001 (in healthy volunteers). One of these, Idebenone, is in its pivotal third phase and could produce the first FDA-approved FA therapy. Now, there is increasing conviction that treatments will soon be developed for Friedreich's ataxia and that the resulting insights will be broadly applicable across a wide range of neurological disorders such as Parkinson's, Huntington's, Alzheimer's, and ALS as well as energy deprivation diseases.

Jennifer Farmer, Executive Director for the Friedreich's Ataxia Research Alliance (FARA) stated, "Everyday is Friedreich's Ataxia Awareness Day for people living with FA. They're constantly trying to educate people and break down barriers due to the rare nature of the disease and disabling effects. Friedreich's Ataxia Awareness Day gives all of us- friends, family, and communities the opportunity to join them in this battle."

Throughout the weekend surrounding FA Awareness Day, events will be held across our country to increase public awareness of Friedreich's ataxia and to raise funds to support the research that promises treatments for this disease. Some of this year's activities include the fourth annual VanSchoick Family Golf Tournament/ Benefit Bash in Statham,

Georgia, the fifth annual Luebbe Family 5K Run/ Walk in Cincinnati, OH, the McCaffrey Irish Dance Benefit in Norwood, MA and the first annual Carolinas' WE Foundation 5K Run/ Walk in Raleigh, North Carolina. These events are generously organized by Friedreich's ataxia families and dedicated community members alike- the VanSchoick Family in honor of their daughters Robbi and Becca, the Luebbe Family in honor of their son Evan, the McCaffrey Family in honor of Barbara McCaffrey and her sister Marianne Crisafulli and the Carolinas' We Foundation comprised by the efforts of the Carolinas' Outback Steakhouse restaurants. Proceeds from these events will help the Friedreich's Ataxia Research Alliance's (FARA) work advancing research to treat and cure Friedreich's ataxia. For more information about these events, please visit <http://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. <http://www.CureFA.org>

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