



Congressional Record

Proceedings and Debates of the 113th Congress, Second Session

WASHINGTON, D.C.

House of Representatives

RECOGNIZING FRIEDREICH'S ATAXIA

HON. GERALD E. CONNOLLY OF VIRGINIA

MR. CONNOLLY: Mr. Speaker, I rise to recognize the third Saturday in May as Friedreich's Ataxia Awareness Day. For my colleagues who may not know, Friedreich's Ataxia is a rare, inherited neuromuscular disorder that damages the nervous system, resulting in symptoms ranging from muscle weakness to speech and vision problems to heart disease.

It is one of 7,000 rare diseases that afflict more than 30 million Americans. Friedreich's Ataxia is caused by the degeneration of the nerves that control the muscular movement of the arms and legs. While usually diagnosed in childhood, Ataxia can appear as early as 18 months or as late as 30 years of age. Most patients are confined to a wheelchair by their early twenties and life expectancy does not extend much beyond early adulthood. While there is currently no effective cure or treatment for Friedreich's ataxia, there are options available for treating its symptoms and accompanying complications, including medications to treat Diabetes and heart conditions.

Since its identification in 1996, there has been considerable research into the causes and potential treatments for Friedreich's Ataxia. Thanks to that research scientists have discovered the genetic mutations that cause this

disease. For example, patients with Friedreich's Ataxia have severely reduced levels of frataxin, a protein that should normally be present in the nervous system, the heart, and the pancreas. Studies also show that Ataxia patients have abnormally high levels of iron in their heart tissue. Continued research and clinical trials at NIH and other medical centers around the globe are giving families struggling with this disease hope that advanced treatments, and perhaps a cure, can one day be found.

On this third Saturday in May, multiple events are being held around the country, including here in Virginia's 11th Congressional District, to increase public awareness about this disease and to raise funds for research and support. I want to particularly recognize the Friedreich's Ataxia Research Alliance, which has an office in Springfield, Va., for its continued contributions to this effort. I wish our local families and advocates, and those in communities across the country, the best of luck with their events.

Mr. Speaker, I ask my colleague to join me in expressing our heartfelt compassion for the patients and families struggling with Friedreich's Ataxia and in recognizing Friedreich's Ataxia Awareness Day.