The Friedreich's Ataxia Research Alliance (FARA) was founded in 1998 by patient families and scientists when there was very little research taking place on FA. The organization set out to fund research and build partnerships needed to advance effective treatments for FA, and provide hope for families and individuals affected by this debilitating disease.

Friedreich's Ataxia (FA) is a debilitating multi-system disease and the most common cause of inherited ataxia; 1 in 100 people are carriers of the FA gene mutation. What begins as difficulty with balance and coordination, progresses over a short period of time to a life altering loss of mobility, energy, speech and hearing, robbing children and young adults of the ability to live active and independent lives. FA also presents serious risk of diabetes and life shortening cardiac disease.

FARA has provided an estimated $30 million towards research, making it the world's largest funder of FA exploration. As a result of their public-private partnerships and multi-stakeholder engagement practices, FARA has 20 different therapeutic candidates currently in their research pipeline, nine of which have reached the clinical trials stage. Two have reached their pivotal, phase 3 trials.

"A rising tide will lift ALL our boats," says Ronald Bartek, President and Co-Founder of FARA. Through partnerships with NORD and other NORD membership organizations, the Alliance for a Stronger FDA and Research!America, FARA advocates to advance and accelerate therapy development for all diseases.

For two consecutive years, FARA staff and volunteers have led state house events across the country for Rare Disease Day®. Their engagement helped make Pennsylvania's event one of the largest, and has led to the establishment of a new Rare Disease Caucus.

NORD is honored to have the Friedreich's Ataxia Research Alliance as a member and to honor them tonight with a Rare Impact Award for their dedication to FA and all rare disease patients and families.