

Cosponsor the National Ataxia Awareness Day Resolution

Ataxia is a progressive group of neurological diseases that is often fatal and affects all ages. September 25 is National Ataxia Awareness Day — a coordinated effort from individuals and Ataxia organizations around the world to help shed light on and fight to end this rare disease. Designating September 25 as National Ataxia Awareness Day through a Simple Resolution will bring awareness needed to improve the lives of the persons and families affected by Ataxia. This resolution will help break down the isolation barriers faced by those with Ataxia because the disease is rare and unknown to most. This resolution can help accelerate development and access to effective treatments for this disease.

About Ataxia

- Ataxia is estimated to affect as many as 150,000 people of all ages, genders, races, and geographic district in the United States.
- Ataxia has a catastrophic effect on patients and their families, both medically and financially.
- Symptoms progress over time, causing lack of coordination, slurred speech, eye movement abnormalities, difficulty walking, tremors, and trouble eating and swallowing.
- Most patients with Ataxia will require the use of wheelchairs and walkers to aid in their mobility.
- Ataxia is an umbrella term used to classify a group of neurodegenerative diseases due to cerebellar dysfunction including, but not limited to: Ataxia Telangiectasia, Episodic Ataxia, Friedreich's Ataxia, Spinocerebellar Ataxia, and Sporadic Ataxia.

National Ataxia Foundation (NAF)

- NAF's primary purpose is to support Ataxia research, provide vital programs and services for Ataxia families, and help in the search for a cure.
- NAF is the only organization in the United States dedicated to the disease that serves all types of Ataxia.
- NAF works closely with the world's leading Ataxia researchers, promoting exchanges of ideas and innovation in Ataxia discovery.

Friederich's Ataxia Research Alliance (FARA)

FARA's 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.

Contact Information

Please contact Lori Shogren, NAF Community Program and Services Director <u>Lori@ataxia.org</u> to cosponsor this legislation.