National Ataxia Foundation

Connecting Ataxia families, researchers, clinicians and the community

ABOUT NAF

The National Ataxia Foundation (NAF) is a non-profit organization dedicated to finding a cure for Ataxia. NAF serves all types of Ataxia and is the only organization of its kind in the United States. NAF works closely with the world's leading Ataxia researchers, promoting exchanges of ideas and innovation in Ataxia discovery.

NAF began with a single doctor's quest to find the cause and cure for Ataxia. John W. Schut, MD founded NAF to relentlessly pursue answers after he lost family members to the disease. Eventually inheriting the disease and succumbing himself, his dream lived on as NAF's efforts to fund research increased – even leading to the first discovery of an Ataxia-causing gene mutation. Today, NAF is guided by the world's most renowned Ataxia scientists and provides the most comprehensive information about the disease.

MISSION STATEMENT

The National Ataxia Foundation is dedicated to improving the lives of people affected by Ataxia through support, education, and research.

NAF INFORMATION

Founded: 1957
Country: USA
Status: 501(c)(3) non-profit
Tax ID: 41-0832903
Focus: Spinocerebellar and Hereditary Ataxias

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PROGRAMS OFFERED

Research

- Ataxia Research Grants
- Research Fellowship Awards
- Young Investigator Awards
- Pioneer SCA Translational Awards
- National Ataxia Registry
- Tissue Donation Program

Education

- Fact Sheets
- Generations Newsletter
- Clinical Trial Readiness Conference
- Ataxia Investigators Meeting

Support Services

- Annual Ataxia Conference
- Patient Support Groups
- Social Network Groups
- Neurologist Resource List
- Ataxia Clinic List

Pictured Above: International attendees of the 2016 Ataxia Investigators Meeting

KEY ACCOMPLISHMENTS

- First Ataxia gene discovered – Spinocerebellar ataxia type 1; identified by a research team led by Dr. Harry Orr and Dr. Huda Zoghbi
- Identified additional Ataxia genes
- Increased understanding in the disease mechanism
- Research discoveries led to diagnostic testing for some types of Ataxia and development of rating scales
- Created educational Ataxia information for patients, families, and caregivers
- Ataxia Patient Registry developed – to connect researchers with patients
- Partnerships developed with key government and private sector entities with an interest in furthering Ataxia treatment options
- Increased big pharma involvement in Ataxia research and drug development
- Started awareness initiatives to increase knowledge of Ataxia in general population and within the medical community
- Coordinated International Ataxia Awareness Day (September 25th) –an annual global awareness campaign

STRATEGIC PLAN

In 2015, NAF's Board of Directors adopted a new strategic plan, mapping out aggressive growth goals. The plan includes greater investment in the foundation to spur innovation and increase efficiency. Utilizing the mantra, "Money buys research, and research finds answers," NAF plans to exponentially increase fundraising efforts in order to provide even more research than the millions of dollars already funded internationally.

NAF EVENTS

Ataxia Investigators Meeting

Launched in 2005, NAF's biennial Ataxia Investigators Meeting brings together the world-leading Ataxia clinicians and scientists who are working to accelerate the pace of Ataxia research, better understand the disease, and develop therapies. In 2018, more than 175 people from 11 countries participated.

Annual Ataxia Conference

Every year, NAF coordinates the world's largest annual Ataxia gathering. For two days, conference attendees meet and learn from world-leading Ataxia researchers and clinicians, network, and reunite with old friends. Hundreds of people – from patients, to caregivers, to medical professionals – attend the conference.

Pictured Above: Dr. Brent Fogel speaking with Annual Ataxia Conference attendees

FUNDRAISERS

- Annual Membership
- Recurring Gift Program
- Memorial/Honor Donations
- Research Contributions
- General Donations
- Special Event Fundraisers
- Walk n' Roll to Cure Ataxia
- 60 for 60 to Cure Ataxia

NAF LEADERSHIP

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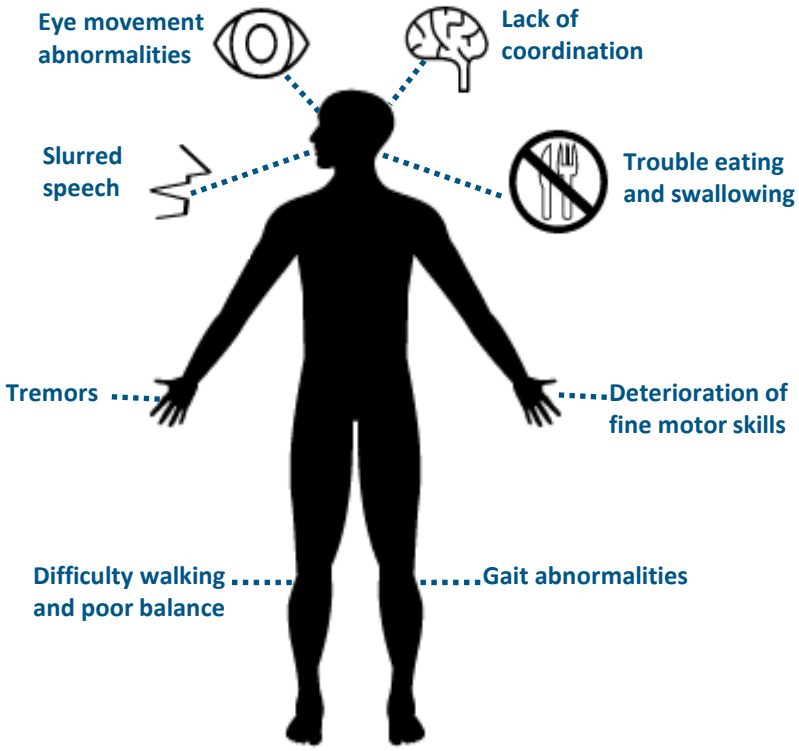
University of Pennsylvania

ATAXIA FACT SHEET

SYMPTOMS

The mechanisms for each specific disease varies, however, they all involve dysfunction related to the cerebellum. The cerebellum is responsible for coordinating various movements and balance. As a result, individuals with Ataxia may exhibit the following symptoms:



ABOUT ATAXIA

Disease Overview

Ataxia is a neurological disease. It is an umbrella term used to classify a group of complex diseases that include:

- Ataxia Telangiectasia
- Episodic Ataxia
- Friedreich's Ataxia
- Multiple System Atrophy
- Spinocerebellar Ataxia
- Sporadic Ataxia

Disease Transmission

Many forms of Ataxia are genetically inherited – either through a dominant or recessive gene. Others do not have a genetic link, occurring sporadically.

Disease Diagnosis

Ataxia is diagnosed using a combination of strategies that may include: medical history, family history, and complete neurological evaluation. Various testing will likely be conducted to rule out other possible disorders with similar symptoms. Genetic blood tests for some forms of hereditary Ataxia may be completed.

Disease Prognosis

Ataxia is progressive and can affect people of all ages. Age of symptom-onset can vary widely from childhood to late-adulthood. Complications from the disease are serious and can be life-shortening.

Individuals with Ataxia often require the use of wheelchairs, walkers, and scooters to aid in their mobility. Symptom medication and therapies can be helpful for some cases. There is no cure for Ataxia.

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