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.

**ABOUT NAF**

**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

**Location:**

600 Highway 169 S.

Suite 1725

Minneapolis, MN 55426

Phone: (763) 553-0020

Fax: (763) 553-0167

Email: naf@ataxia.org

www.ataxia.org

**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

**NAF STAFF**

- **Andrew Rosen**
  Executive Director

- **Joel Sutherland**
  Development Director

- **Sue Hagen**
  Patient and Research Services Director

- **Lori Shogren**
  Community Program and Services Director

- **Stephanie Lucas**
  Communications Manager

- **Mollie Utting**
  Communications Coordinator

- **Jon Wegman**
  Development Associate

- **Mary Ann Peterson**
  Research Assistant

- **Kelsey Trace**
  Research Associate

- **Nick Gullickson**
  Finance Associate
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.

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

## 2018 Board of Directors

- **William P. Sweeney**
  President; Executive Committee Member
- **Camille Daglio**
  Vice President; Executive Committee Member
- **Charlene Danielson**
  Treasurer; Secretary Executive Committee Member
- **Executive Committee Members**
  - Joseph DeCrescenzo
  - Sam Kirton
  - Michael Leader
  - John Mauro
  - Executive Committee Member
- **Lawrence Schut, MD**
  Medical Liaison
- **Harry T. Orr, PhD**
  NAF Research Director
- **Susan Perlman, MD**
  NAF Medical Director
- **Laura Ranum, PhD**
  Associate Research Director
- **Directors**
  - David Brunnert
  - Michael Cammer
  - Harold Crawford
  - Cindy De Mint
  - Wilson Romero
  - Greg Rooks
  - Marilyn Schut Lee
  - Linda Snider, MD
  - Dave Zilles
- **Board Member Emeritus**
  - Julie Shuur

## 2018 Medical Research Advisory Board

### Research Director
- **Harry T. Orr, PhD**
  Director of Institute for Translational Neuroscience Tulloch Professor of Genetics University of Minnesota

### Associate Research Director
- **Laura Ranum, PhD**
  Professor of Molecular Genetics and Microbiology Director, Center for Gene Discovery and Neurological Disease University of Florida, College of Medicine

### Medical Director
- **Susan Perlman, MD**
  Clinical Professor University of California, Los Angeles, Neurological Services David Geffen School of Medicine

### Medical Liaison
- **Lawrence Schut, MD**
  Maple Lake, MN

### Advisory Board Members
- **Tetsuo Ashizawa, MD, FAAN**
  Methodist Hospital Research Institute
- **Khalaf Bushara, MD, MRCP**
  University of Minnesota
- **Beverly Davidson, PhD**
  Children’s Hospital of Philadelphia
- **Brent L. Fogel, MD, PhD**
  David Geffen School of Medicine
- **Christopher M. Gomez, MD, PhD**
  University of Chicago
- **Sheng Han Kuo, MD**
  Columbia University
- **Albert La Spada, MD, PhD, FACMG**
  University of California
- **David Lynch, MD**
  University of Pennsylvania
- **Puneet Opal, MD, PhD**
  Feinberg School of Medicine Northwestern University
- **Gulin Oz, PhD**
  Center for Magnetic Resonance Research University of Minnesota
- **Henry Paulson, MD, PhD**
  University of Michigan Medical Center
- **Christopher Pearson, PhD**
  The Hospital for Sick Children Toronto, Ontario
- **Stefan Pulst, MD**
  University of Utah Health Sciences Center
- **Liana Rosenthal, MD**
  Johns Hopkins University
- **Jeremy D. Schmahmann, MD**
  Harvard Medical School
- **Vikram Shakkottai, MD, PhD**
  University of Michigan
- **S.H. Subramony, MD**
  University of Florida
- **George “Chip” Wilmot, MD, PhD**
  Emory University
- **Robert B. Wilson, MD, PhD**
  University of Pennsylvania
**ATAXIA FACT SHEET**

**150,000**

Americans have Ataxia

**1 in 5,000**

Worldwide

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**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:

- **Eye movement abnormalities**
- **Slurred speech**
- **Lack of coordination**
- **Trouble eating and swallowing**
- **Tremors**
- **Difficulty walking and poor balance**
- **Deterioration of fine motor skills**
- **Gait abnormalities**

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**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
- Friedrich’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.