

## Ataxia Resources

The National Ataxia Foundation is dedicated to providing the most current and relevant information about Ataxia. Single and complimentary copies are available to order by using the form on the reverse side of this fact sheet or you may place an order on our website at [www.ataxia.org](http://www.ataxia.org) or send an email to [naf@ataxia.org](mailto:naf@ataxia.org)

### FREQUENTLY ASKED QUESTIONS ABOUT...

**Ataxia**—Describes the cause, method of diagnosis, conditions that cause Ataxia to appear and symptomatic treatment recommendations. *Also available in Spanish.*

**Ataxia Classification**—Uses the current terminology to describe the difference between acquire, genetic, idiopathic and unknown Ataxia classifications.

**Cognition & Emotion in Cerebellar Disorder**—Provides research driven information on how the cerebellum plays a role in thought, reasoning, motivation, memory and feelings

**Coordinative PT for Ataxia**—Provides a physical therapy approach that aims to improve balance and coordination with instructions and diagrams of exercises to use.

**Episodic Ataxia**—Describes Episodic Ataxia types 1 and 2, symptoms, prognosis, inheritance pattern, diagnosis and other information. *Also available in Spanish.*

**Friedreich's Ataxia**—Includes a brief history of Friedreich's Ataxia, the symptoms, causes, prevalence, age of onset, diagnosis and the research taking place for Friedreich's Ataxia.

**Gene Testing for Hereditary Ataxia**—Answers questions about genetic testing for the hereditary Ataxias, reasons to consider genetic testing and suggested guidelines.

**Medications for Ataxia Symptoms**—List of Ataxia symptoms with off-label medications that can be used under a doctor's supervision.

**CoRDS Registry**—Information on how to enroll in the centralized international patient registry for all rare diseases; it is based at Sanford Research and partners with NAF.

**Preparing for a Visit with the Neurologist**—Provides important information to assist you in having productive appointments with your physician both for diagnosis and treatment options.

**Spinocerebellar Ataxia**—Provides information on the symptoms, prognosis, diagnosis and the location of the defective gene for the following types of SCA: 1,2,3,5,6,7,8,10,14.

**Sporadic Ataxia and Multiple System Atrophy**—Describes symptoms for the neurodegenerative disease with no known family history. Lists other names commonly used, causes and symptoms.

**Brain Tissue Donation**—Answers questions about why tissue donation is important to Ataxia research and the process for donating tissue for medical research.

### BOOKLETS, BROCHURES AND FLIERS

**Ataxia...the Facts**—Flier that describes the objectives of the National Ataxia Foundation and a brief description of all the forms of ataxia. Excellent for use at fundraisers and to build Ataxia awareness.

**Spinocerebellar Ataxia: Making an Informed Choice about Genetic Testing**—By the University of Washington Medical Center, an 18-page booklet that reviews information about dominantly inherited forms of Spinocerebellar Ataxia.

**Children with Ataxia Stories**—Short stories written by Parents and Grandparents of Children with Ataxia, who offer a candid perspective on how Ataxia has forever changed their lives yet they share their hope for the future.

**Understanding Genetics**—By Linda Hanner and Marha A. Nance, MD. This illustrated 30-page booklet provides information on genetics, inheritance patterns, genetic disease and family trees. *Third edition updates by Sarah Kreykes, MS.*

**Evaluation and Management of Ataxic Disorders for Physicians**  
*By Susan Perlman, MD*

This resource is intended to inform and guide physicians who may be caring for patients with ataxic symptoms or who have been diagnosed with Ataxia. It will provide health care practitioners with a vocabulary to aid in the understanding of what is and is not Ataxia, diagnostic protocols for use in counseling and managing the ataxic patient. Published in 2007.

### Healing Wounded Doctor-Patient Relationships

By Linda Hanner with contributions by John J. Witek, MD and doctors and patients around the nation.

This book is packed with information that anyone who ever goes to a doctor for any reason deserves to know and that every professional who wants to maximize his or her healing power must understand.

### Living with Ataxia: AN Information and Resource Guide

By Martha Nance, MD

This illustrated book provided a compassionate, easy to understand explanation of Ataxia with ideas on how to live with Ataxia. It is an excellent tool for building awareness for those who do not know what Ataxia is or how it affects a person who has Ataxia. This 2nd Edition was published in 2003.

### Managing Speech and Swallowing Problems: A Guidebook for People with Ataxia

By G.N. Rangamani, PhD with contributions from Douglas E. Fox, MS

This 60-page booklet is an excellent resource for those who struggle with the speech and/or swallowing changes which can occur in the person with an Ataxia disorder. It is an easy to understand booklet with straight-forward and realistic suggestions for speed and swallowing management. This 2nd edition was published in 2006.

### Ten Years to Live

By Henry J. Schut

This is the story of the Schut family's struggle with hereditary Ataxia and the impact it had on this extended family. It is dedicated to the author's brother, Dr. John W. Schut who was committed to the cause of finding a cure for Ataxia, the disease that claimed his life.

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## ORDER FORM

Orders can be made on-line at [www.ataxia.org](http://www.ataxia.org), or you may email or mail this from to, [naf@ataxia.org](mailto:naf@ataxia.org) or National Ataxia Foundation, 600 HWY 169 S., Suite 1725, Minneapolis, MN 55426

- Ataxia
- Ataxia (Spanish)
- Classification of Ataxia
- Cognition & Emotion
- Coordinative PT for Ataxia
- Episodic Ataxia
- Episodic Ataxia (Spanish)
- Friedreich's Ataxia
- Gene Testing for Hereditary Ataxia

#### Spinocerebellar Ataxia Types

- SCA 1
- SCA 2
- SCA 3
- SCA 5
- SCA 6
- SCA 7
- SCA (Spanish)
- SCA 8
- SCA 10
- SCA 14

- Medications for Ataxia Symptoms
- CoRDS Registry
- Preparing for a Visit with the Neurologist
- Sporadic Ataxia and Multiple System Atrophy
- Brain Tissue Donation
- Ataxia...The Facts
- SCA: Making an Informed Choice
- Children with Ataxia Stories
- Understanding Genetics

#### Below Resources have a \$6.50 Shipping & Handling fee

- Evaluation & Management of Ataxia Disorders
- Healing Wounded Doctor-Patient Relationships
- Living with Ataxia: An Information & Resource Guide
- Ten Years to Live

Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Order Total: \$ \_\_\_\_\_

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