

ATAXIA RESOURCES

From the National Ataxia Foundation

Fact Sheets - Single copies are free Frequently Asked Questions about . . .

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

Ataxia-Telangiectasia (A-T) – Describes this childhood type of ataxia, its symptoms, prognosis, the genetic patterns and sources of support and methods of treatment.

Classification of Ataxia – Includes a brief history of ataxia classification, the currently known inherited ataxias, their inheritance pattern and whether a gene test is available with names of the inherited and sporadic ataxias.

Cognition and Emotion in Cerebellar Disorders – Provides research driven information on how the cerebellum plays a role in areas such as thought, reasoning, motivation, memory and feelings.

Diet for Ataxia – Includes diet suggestions for discussion purposes with your physician to include the purpose of an ataxia diet, foods to avoid and information on gluten ataxia.

Episodic Ataxia – Describes Episodic Ataxia types 1 and 2, symptoms, prognosis, inheritance pattern, diagnosis and information on the patient registry for those with episodic ataxia. Also available in Spanish.

Financial Planning – Offers guidelines for parents and spouses of a person with a disability to assure that their family member with a disability will have a quality of life should they, themselves, become disabled or when they are no longer here using the four different components of the Life Planning approach: *The Life Plan*, *The Funding Plan*, *The Legal Plan*, and *The Plan Management*.

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.

National Ataxia Registry – Explains the importance of a patient registry for ataxia research and answers questions about the process and the security of this web-based patient registry.

Patient Registries – Patient Registries are essential for ataxia researchers to move into the clinical trial phase of research. This fact sheet provides the web addresses of three important patient registries for those with ataxia.

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 Spinocerebellar ataxia (SCA) 1, 2, 3, 5, 6, 7, 8, 10, 14. SCA 7 is also available in Spanish.

Sporadic Olivopontocerebellar Atrophy (OPCA) – Describes symptoms for this neurodegenerative disease with no known family history. Lists other names commonly used, causes and symptoms.

Tissue Donation – Answers questions about why tissue donation is important to ataxia research and the process for donating tissue for medical research.

Brochures and Fliers

FAQs about Hereditary Ataxia – This envelope-sized brochure provides information on ataxia and the work of the National Ataxia Foundation. Multiple copies available upon request.

Ataxia . . . The Facts – a two sided flier that describes the objectives of the National Ataxia Foundation and a brief description of all the forms of ataxia, the symptoms, progression and diagnosis. Excellent for use at fundraisers and to build ataxia awareness. Multiple copies available upon request.

Booklets

Single copies are free

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 and genetic testing for spinocerebellar ataxia.

Understanding Genetics – by Linda Hanner and Martha A. Nance, M.D. This illustrated 30 page booklet provides information on genetics, inheritance patterns, genetic disease and family trees.

Newsletter

Single copies are free

Generations – the National Ataxia Foundation's official quarterly newsletter that includes ataxia research updates, personal stories of living with ataxia, ataxia support group meetings and up-to-date information related to ataxia. Mailed to members of the Foundation.

ORDER FORM

The following materials are available in single copies at no charge. Please place an X next to the item(s) you wish to receive. You may also find these resources available for downloading on the National Ataxia Foundation's website at www.ataxia.org.

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Tax deductible donations are always appreciated and help the Foundation continue its mission to improve the lives of persons affected by ataxia through support, education, and research.

Mail order form to:

National Ataxia Foundation, 2600 Fernbrook Lane No. Suite 119, Minneapolis, MN 55447

ATAXIA RESOURCES FOR PURCHASE

ATAXIA RESOURCES

Evaluation and Management of Ataxic Disorders for Physicians

by Susan Perlman, M.D.

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 defining the types and causes of ataxia and resources for use in counseling and managing the ataxic patient. Consider buying one for your neurologist and other health care providers. Published in 2007. \$5.00

Healing Wounded Doctor-Patient Relationships

By Linda Hanner with contributions by John J. Witek, M.D. 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. \$10.00

Living With Ataxia: An information and resource guide

by Martha Nance, M.D.

This illustrated book provides a compassionate, easy to understand explanation of ataxia with ideas on how to live well 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 second edition was published in 2003. \$14.00

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

by G.N. Rangamani, Ph.D. with contributions from Douglas E. Fox, M.S.

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 speech and swallowing management. This second edition was updated in 2006. \$7.50

FICTION & PERSONAL STORIES

Ten Years to Live

By Henry J. Schut.

This is the story of the Schut's family 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. \$8.75

Summer Born: A Life with Cerebellar Ataxia

By Cheryl Wedesweiler

Although the characters are fictional, the story is based on the author's real life experiences with having cerebellar ataxia.

\$15.95

There's Nothing Wrong with Asking for a Little Help. . . and other myths

By Dave Lewis

The story about one man's experiences in living with Friedreich's ataxia. Dave spent the last three years of his life writing his memoir to provide information and inspiration to countless others. Proceeds from the book purchased through NAF will be used to support promising Friedreich's ataxia research. \$15.95

Ataxia Resources for Purchase, continued

COOK BOOKS

Recipes and Recollections

By Kathryn Hoefler Smith

Dedicated to the memory of her daughters who had Friedreich's ataxia, Kathryn Hoefler Smith has taken the handwritten cookbook her mother-in-law made for her sons and their families and duplicated it in 2003. It is full of delicious recipes and recollections. Perfect for FRDA research fundraisers. \$10.00

Cooking for a Cause

By Julie Karjalahti for FRDA research.

This 177 page cookbook has kid's recipes, fun craft recipes, along with the usual desserts, breads, beverages and other recipes you would expect from a good cookbook. Many of the recipes are contributed by Minnesota cooks, so if you are looking for a recipe for an authentic Midwest "hotdish" or Jello Salad, this is the cookbook for you. \$12.00

| Title | Cost | Quantity | Total Cost |
|---|-------------|-----------------|-------------------|
| Evaluation and Management of Ataxic Disorders for Physicians | \$5.00 | | |
| Healing Wounded Doctor-Patient Relationships | \$10.00 | | |
| Living With Ataxia: An information and resource guide | \$14.00 | | |
| Managing Speech and Swallowing Problems: A Guidebook for People with Ataxia | \$7.50 | | |
| Ten Years to Live | \$8.75 | | |
| Summer Born: A Life with Cerebellar Ataxia | \$15.95 | | |
| There's Nothing Wrong with Asking for a Little Help . . . and other myths | \$15.95 | | |
| Recipes and Recollections | \$10.00 | | |
| Cooking for a Cause | \$12.00 | | |
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