

RESOURCES FOR PATIENTS WITH ATAXIAS

INFORMATION:

National Ataxia Foundation (NAF)

1725-600 Highway 169 S.

Minneapolis, Minnesota 55426

Phone: (763) 553-0020

Website: www.ataxia.org

- *Information about symptoms, treatments and causes can be found here:* www.ataxia.org/what-is-ataxia/
- *Follow them on Facebook:* www.facebook.com/ataxiafoundation/

Ataxia Canada

1751 Richardson – 5400

Montreal, Qc H3K 1G6

Phone: 1-(855)-321-8684

Website: www.lacaf.org

- *Information about symptoms and the different types of Ataxia's can be found under the "Ataxias" drop down menu.*

SCASource

Website: www.scasource.net

- *This is a website dedicated to research on SCAs and related ataxias.*
- *Information about types of Ataxias:* www.scasource.net/what-is-ataxia/
- *Follow them on twitter:* www.twitter.com/SCASource

SUPPORT GROUPS:

Hope for Ataxia

Contact form: www.hopeforataxia.org/contact/

Website: www.hopeforataxia.org

- *This is a global support group. For information and to sign up for a meeting:* www.hopeforataxia.org/gasg/

Living with Ataxia

Website: www.livingwithataxia.org

- *This is an online supportive place to connect with others. Discussions on symptoms, treatment, strategies and support, and research.*

Broadway for Ataxia

Website: www.broadwayforataxia.org

Enriching the lives of people with Ataxias through theatrical arts.

National Ataxia Foundation (NAF)

Support group information: www.ataxia.org/support-groups/

- *NAF Community Ataxia support group: **Facebook Group:** <https://www.facebook.com/groups/NAFmail>*
- *Under 30 with Ataxia support group: **Facebook Group:** <https://www.facebook.com/groups/Under30withAtaxia/>*
- *Spouses and partners of loved ones with Ataxia support group: **Facebook Group:** <https://www.facebook.com/groups/AtaxiaSpousesAndPartners/>*
- *Parents of kids with Ataxia support group: **Facebook Group:** <https://www.facebook.com/groups/ParentsOfKidsWithAtaxia>*
- *African Americans with Ataxia support group: **Facebook Group:** <https://www.facebook.com/groups/501238100417901/>*
- *Military members with Ataxia talking team room: **Facebook Group:** <https://www.facebook.com/groups/922015755298690>*

RESEARCH:

Coordination of Rare Diseases at Sanford (CoRDS)

Contact form: www.research.sanfordhealth.org/rare-disease-registry/contact-us

Website: <https://research.sanfordhealth.org/rare-disease-registry>

Phone: 1-(605)-312-6300

- *CoRDS is a registry for rare diseases.*

ClinicalTrials.gov

Website: www.clinicaltrials.gov

- *ClinicalTrials.gov is an international database of clinical research studies.*
- *You can search for studies by disease/condition and location.*
- *Learn about clinical studies, what they are, how to participate, and how participants are protected here: www.clinicaltrials.gov/ct2/about-studies/learn*

RESOURCES FOR PATIENT'S WITH FRIEDEICH'S ATAXIA

Friedeich's Ataxia Research Alliance

533 W Uwchlan Ave

Downingtown, PA 19335

Phone: (484) 879-6160

Website: www.curefa.org

- *Information about causes and treatments can be found here: www.curefa.org/whatis*
- *Patient registry: www.curefa.org/patient-registry*

Connect FA

5320 Legacy Drive

Plano, TX 75024

Phone: (972) 865-2219 or (855) 55-RETA (7382) (toll free)

Website: www.connectfa.com

- *Information about symptoms and progression can be found here: www.connectfa.com/resources/*

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- *Read the Friedeich's Ataxia fact sheet here: www.ataxia.org/fact-sheets/*