# **Newly Diagnosed Resources**



## 1.Become a FREE member of NAF & Sign Up for NAF emails - www.ataxia.org/JoinNAF

- The National Ataxia Foundation (NAF) is the largest Ataxia focused nonprofit organization in the US. NAF's mission is to accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia.
- Follow NAF on social media to stay up to date with the latest news, connect with the Ataxia community, and to learn more about NAF.
  - Instagram: @ataxiafoundation
  - Facebook: Join the National Ataxia Foundation Facebook group.
  - X formally Twitter: @NAF\_Ataxia
  - YouTube: <u>National Ataxia Foundation</u>
- Membership is free and allows you to connect with a community of Ataxia patients and family members. Other membership benefits include:
  - Personalized news, research, and clinical trial opportunities.
  - Early access to free educational webinars.

## 2. Join the CoRDs Ataxia Patient Registry

- The purpose of a patient registry is to advance the development of treatments for a disease by connecting researchers, drug developers, and healthcare professionals with those affected. Patient registries are critically important for rare diseases like Ataxia. NAF has partnered with Sanford Research to establish the CoRDS Ataxia Patient Registry. Join CoRDs!

## 3. Consider scheduling an appointment with an Ataxia Center of Excellence or Ataxia provider in your area

- NAF's Neurologists and Specialty Clinics map is a regularly updated resource of many providers across the US and Canada who specialize in Ataxia or treat Ataxia patients. <a href="https://www.ataxia.org/neurologists-and-specialty-clinics/">https://www.ataxia.org/neurologists-and-specialty-clinics/</a>
- 4.Learn more about Ataxia including how to prepare for a doctor's appointment, some treatments for common symptoms, and more. <a href="https://www.ataxia.org/what-is-ataxia">https://www.ataxia.org/what-is-ataxia</a>
- 5. Find and join a support group in your area. <a href="https://www.ataxia.org/support-groups/">https://www.ataxia.org/support-groups/</a>

## 6. Consider attending NAF's hybrid Annual Ataxia Conference (AAC)

- This conference typically takes place in March of each year.
- Stay tuned for more information on the next AAC! https://www.ataxia.org/annual-ataxia-conference/

## 7. Delve deeper into the clinical trial process via PrepRARE.

- PrepRARE is a series of webinars, articles, and other information to educate members about all stages of the clinical trial process and make sure that you are ready to make informed decisions about participation when a new clinical trial begins recruitment. <a href="https://www.ataxia.org/preprare/">https://www.ataxia.org/preprare/</a>

8.Learn if you are eligible to participate in the CRC-SCA Natural History Study. <a href="https://www.ataxia.org/crc-sca/">https://www.ataxia.org/crc-sca/</a> or other Ataxia Studies: <a href="https://www.ataxia.org/help-develop-new-treatments/#ResearchParticipation">https://www.ataxia.org/help-develop-new-treatments/#ResearchParticipation</a>

## 9. Become an advocate for Ataxia

- There are many ways to become an advocate for ataxia including signing up for advocacy emails and visiting our advocacy page for more info about ongoing initiatives. <a href="https://www.ataxia.org/advocacy/">https://www.ataxia.org/advocacy/</a>
- International Ataxia Awareness Day: September 25th
- 10.Get involved in fundraising! <a href="https://www.ataxia.org/ways-to-give/">https://www.ataxia.org/ways-to-give/</a>

