

SCA1, SCA2, and SCA3 Genetic Counseling and Testing Program



A free program for participants who qualify

Program Description:

The National Ataxia Foundation (NAF) is offering free virtual genetic counseling and free genetic testing for individuals who have a biological family member with a confirmed diagnosis of SCA1, SCA2, or SCA3. Health insurance is not required for participation in this program.

Why?

Genetic testing to confirm a diagnosis of Ataxia can be an incredibly useful tool for persons with a family history of Ataxia. Genetic testing can help inform decisions around family planning, healthcare/lifestyle choices, and professional/financial planning. Genetic testing is also often a requirement for participation in clinical trials for SCAs.

NAF, in partnership with our Drug Development Collaborative, is now offering this program to overcome any obstacles that may prevent individuals from receiving genetic counseling and testing. Eligible participants will receive virtual genetic counseling at no-cost to them. After counseling, if the participant and genetic counselor determine that testing is the right decision, genetic testing for SCA1, SCA2, and SCA3 will be offered at no-cost to the participant.

Who is eligible:

At this time, the Genetic Counseling and Testing Program is available to a person who is at-risk for SCA1, SCA2, and/or SCA3 because they have a family member with a confirmed genetic diagnosis. Participants must live in the United States, be 18 years of age or older, and become a free member of NAF to participate. You do not need a referral from a physician to participate.

How it works:

1. Contact NAF (research@ataxia.org) to determine if you are eligible for no-cost genetic counseling.
2. Become a FREE member of NAF at www.ataxia.org/JoinNAF.
3. Enroll in the program using a secure on-line portal.
4. Schedule your virtual appointment with a genetic counselor.
5. Attend a pre-test genetic counseling session.
6. If you choose to proceed with genetic testing, you will receive a DNA testing kit in the mail. Follow the instructions in the prepaid postage envelope.
7. Attend a virtual post-test genetic counseling session.
8. You are encouraged to share your results with your neurologist, as well as the National Ataxia Foundation by emailing research@ataxia.org. If you received a positive diagnosis, you will be informed of studies and clinical trials for which you may qualify. If you test negative, we will update you NAF membership record.

A genetic counselor will review your medical and family histories including any prior test reports that are available and recommend the most appropriate genetic testing for you. Based on the family and medical histories, it is possible that the sponsored test option is not medically appropriate and a different non-sponsored test may be recommended. Your genetic counselor will review all available testing options with you at your visit.

How to get started:

If you or a family member are eligible because you have a direct relative who has genetically tested positive for SCA1, SCA2, or SCA3, please contact NAF's Research Department at research@ataxia.org.