Mass General Brigham IRB
APPROVAL EFFECTIVE DATE
2/12/2024

The Massachusetts General Hospital Ataxia Center is recruiting people with ARSACS for a new study

Study Name:
Social network analysis in ataxia patients: exploring correlations with quality of life and functional outcomes.

What we are studying:
The potential importance of social networks for quality of life and wellbeing in patients with ataxia has historically been overlooked. We aim to explore the importance of social connectivity in the ataxia community. We will achieve this by collecting survey data from patients with cerebellar ataxia regarding their social networks, quality of life, and physical function. This study will help determine whether someone's social circle impacts their disease and overall wellbeing, and we will then be in position to use this information to develop novel approaches to improve the lives of individuals with ataxia.

Who might qualify:
We are looking for people who are 18 years or older who speak English and have a confirmed genetic diagnosis of autosomal recessive spastic ataxia of Charlevoix-Saguenay (ARSACS).

What you are asked to do in the study:
We ask that you join us for a one-time 1-hour meeting on Microsoft Teams to complete five surveys with our research coordinator.

For more information:
To learn more about this study:
Contact the study coordinator, James Concepcion, at 617-726-4961 or jconcepcion2@mgh.harvard.edu
After you learn more, you can decide to join or not.

Thank you for considering this research study.

Jeremy Schmahmann, MD
Founding Director, Massachusetts General Hospital Ataxia Center
A Center of Excellence of the National Ataxia Foundation and the MSA Coalition