

January 15, 2014

Study of the experiences and opinions regarding predictive testing in Friedreich ataxia

The Genetic Counseling program at Arcadia University and Karlla Brigatti, the neurogenetics genetic counselor who is part of The Friedreich ataxia program at The Children's Hospital of Philadelphia (CHOP) want to learn more about the attitudes and experiences in the FA community with predictive genetic testing, which is testing someone at risk for the condition (for example, the sibling of someone with FA) when that person does not have any obvious features of the condition. This information will help researchers better understand how the FA community feels about this issue and better develop ways to potentially work with presymptomatic individuals in drug trials and clinical practice.

We are looking for individuals over the age of 18 who have FA or are related to someone with FA to answer a brief survey online.

About the study:

- This online survey should take about 15-20 minutes to complete
- No identifying information is obtained in the survey
- This survey has been approved by the Institutional Review Board of Arcadia University

Questions can be directed to Kim Glaser at kglaser@arcadia.edu, Karlla Brigatti at brigatti@email.chop.edu, or Lisa Kessler at kesslerl@arcadia.edu

Please click on this link below if you are interested in participating or want to learn more

<https://www.surveymonkey.com/s/7CKH2J6>