



**Study Title:** The Friedreich's Ataxia Health Index Study (FA-HI): Development of Clinically Relevant Disease Specific Patient Reported Outcome Measures for Use in Drug Labeling Claims in Friedreich's Ataxia Therapeutic Trials

**Principal Investigator:** Chad Heatwole, MD, MS-CI

**Institutional Affiliation:** University of Rochester, Department of Neurology

This form describes a research study for patient-reported health outcomes related to FA. The study aims to identify the symptoms that have the greatest impact on quality-of-life for individuals with FA. The results of this study will help guide future research involving FA patients. This study is being conducted in collaboration with the Friedreich's Ataxia Research Alliance (FARA).

### **WHO CAN PARTICIPATE?**

- U.S. residents
- Participants with a confirmed diagnosis of FA
- Adults, ages 18 or older
- Children, ages 8-17, with parental consent; if the child is age 13-17, only the child should complete the survey
- Parents of children age 0-12; both parent and child can complete the survey for children ages 8-12.

### **WHAT IS INVOLVED?**

Completion of an online survey, which includes demographic questions and FA symptom questions. The survey will take approximately 20 minutes to complete and all responses will be strictly confidential. The survey answers will be completely anonymous. Participants can skip any questions they don't wish to answer.

**For Adults and Children ages 8-17**, click this link to participate:

<https://is.gd/fasurvey>

**For Parents of Children ages 0-12**, click this link to participate:

<https://is.gd/facaregiver>

### **MORE INFORMATION:**

Any questions or comments can be directed to the study coordinator, Christine Zizzi, at: 585-276-7772 or [Christine.Zizzi@chet.rochester.edu](mailto:Christine.Zizzi@chet.rochester.edu)

Note: If you would prefer to complete the survey on paper or over the phone, please contact Christine Zizzi.