





FA Neurobooth Research Study in Boston

Individuals with Friedreich's ataxia and age-matched healthy controls

Why is this research important?

The goal of this project is to create technologies that can sensitively identify and measure progression of motor changes in Friedreich's ataxia (FA). These technologies would support early detection of FA signs and symptoms and facilitate drug development efforts by providing objective and sensitive digital measures for use as endpoints in clinical trials in FA, including early-stage disease.

Who can participate?

- People 8-30 years old with a diagnosis of Friedreich's ataxia, with or without symptoms.
- Healthy controls without a neurological or musculoskeletal condition or other condition that affects movement or thinking.
- Ability to walk with or without an assistive device.

What happens if I sign up?

- You will be asked to participate in this study every 6 months for a total of 4 visits.
- You will be guided through a set of neurological tasks while wearing lightweight, non-invasive sensors. These tasks include tracking objects with your eyes, solving puzzles on a computer screen, speaking words aloud, moving your arms and legs, and walking back and forth down a hallway. During this time, we will be recording your movement and speech with cameras, eye tracking devices, and microphones.
- You will be asked to participate in a clinician-performed neurological examination.
- You will be asked to complete daily function and quality-of-life surveys at home.

Will I be paid for this study?

- You will be compensated \$100 each time you participate in this study.
- We will reimburse for parking and travel costs (airfare and one night of lodging) up to \$800.



Please contact us if you are interested in learning more about this study.

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