

The Collaborative Clinical Research Network in Friedreich's Ataxia (CCRN in FA) is an international network of clinical research centers, where physicians, researchers and patients work together to advance treatments and best practices for management and treatment of Friedreich's ataxia.

The Children's Hospital of Philadelphia (CHOP) is one of the sites participating in this network. The CCRN in FA is funded by the Friedreich's Ataxia Research Alliance (FARA). The research centers involved in this network, including CHOP, run a study called Clinical Outcome Measures in Friedreich's Ataxia (FACOMS). This is a natural history study with the following objectives:

- Collect data every year to understand progression of FA and be able to quantify change in progression over time
- Develop and validate outcome measures (timed walk tests, vision tests) that can be used in future clinical trials
- Expand the network of clinical research centers working on Friedreich ataxia
- Make design and implementation of clinical trials more efficient and effective
- Collect biological samples such as cheek swabs and blood to identify and study biomarkers involved with the disease process and quantify the change in these markers over time

You may be eligible to take part if:

- You have a confirmed diagnosis of Friedreich's ataxia
- A parent/guardian gives permission for you to participate if you are under 18 years of age

The sites in this network provide opportunities for individuals to participate in the FACOMS study annually.

If you would like to participate in this study at the Children's Hospital of Philadelphia, please call the CHOP Friedreich Ataxia Program number at (267) 426-7538.

The Principal Investigator at this site is Dr. David Lynch.