

Dear Ataxia UK member:

We wanted to share news of a new research study that might interest you or someone in your family. The purpose of this study is to understand the experiences of people living with Friedreich's Ataxia, or FA, and how FA impacts daily life. The study will also be collecting information about the experiences of people who provide care for someone with FA, including parents and spouses.

The findings of this study will describe the impact of FA on individuals and families, and it will contribute to research that can be used to inform healthcare decision making for FA.

Who is eligible to participate?

To participate you need to:

- Be 18 years of age or older
- Live in the United Kingdom
- Be fluent in English
- Have a confirmed diagnosis of FA **OR** be the primary caregiver of someone with FA
 - If you are a primary caregiver of someone with FA, you may respond on behalf of a child or adult of any age
 - Primary caregivers can include parents, legal guardians, spouses, or other friends or relatives that provide unpaid care; they should be the main person (or one of the main people) who helps with healthcare needs and everyday activities

What is involved?

If you are eligible to participate in the study, you will complete a one-time, virtual interview. If you are someone living with FA, your interview will last about one hour (60 minutes), and you will be compensated £50 for your time and expertise.

If you are a caregiver, your interview will last about an hour and a half (90 minutes) and you will be compensated £75. Caregiver interviews will include two parts: (1) responding to questions on behalf of the person living with FA, and (2) describing your experiences of providing care.

Your participation in the study will be kept private and you will not be identifiable from the research in any way.

More information:

If you are interested in participating, please email Andrea Bever, the project manager at Broadstreet to schedule a short phone call to learn more about the study and to find out if you are eligible to take part.

Thank you for considering collaborating in this important study!

Contact details:

FAstudy@broadstreetheor.com