

Clinical Trial Readiness for POLG-Related Mitochondrial Disease and Ataxia: A Prospective, Longitudinal Study Identifying Sensitive and Ecologically Valid Biomarkers (C4TR-POLG)

Summary Participant Information Sheet

We would like to invite you to take part in a research study.

Before you decide whether to take part, it is important that you understand why we are doing this research and what it will involve.

This is a brief summary of the study. If after reading it you are interested in taking part, please read the full Participant Information Sheet for more details.

You are free to decide whether to take part. If you decide not to, it will not affect the care you receive.

About the Study

This study is for adults (ages 16 years and over) diagnosed with POLG-related mitochondrial disease.

We would like to learn about:

- The symptoms of ataxia (coordination, movement, balance and speech problems) and disease burden of POLG-related mitochondrial disease
- The best ways to measure how this condition changes over time

This research study may enable researchers and clinicians to find better ways of tracking ataxia symptoms associated with the condition more accurately. It may also inform the design of future clinical trials to test new treatments.

If you take part, you will come to the Clinical Ageing Research Unit (CARU) in Newcastle for **three study visits** over a **12-month** period.

Each study visit will last for a few hours. We will:

- Conduct clinical assessments including physical examinations
- Ask you to complete health questionnaires
- Perform walking and balance activities in a specialist gait laboratory
- Take some blood samples
- Ask you to wear small sensors to measure your movements at home.

We will also collect relevant information from your medical records.

Assistance with travel costs associated with taking part in this study will be provided.

If you have any questions, please contact us on:

Tel: [XXXXXX XXXXXXXX] Email: [XXXXXXXXXXXXXXXXXX]