

## **Volunteers needed to take part in a European Friedreich's ataxia natural history study**

### **What is the purpose of the study?**

The European Friedreich's ataxia Consortium for Translational Studies (EFACTS) is a 4 year study supported by the European Commission that will gather vital information about the progression of Friedreich's ataxia (FA) which can be delivered to patients to give them a better knowledge of their prognosis and the development of their condition. The purpose is to generate a large FA patient database, alongside an integrated clinical and natural history database; this will be linked to a biological samples repository. It also aims to define a panel of clinical assessment tools for use in future trials. The UCL Institute of Neurology is one of the 15 groups from 7 European countries participating in the EFACTS project.

### **What will happen to those who take part?**

If you do decide to take part you will be required to attend an initial consultation where consent will be sought for participation in the study, which will either be carried out at the National Hospital for Neurology and Neurosurgery or on a home visit. In the same consultation, participants will undergo a medical check-up where their Scale for Assessment and Rating Ataxia (SARA) score will be determined, 9-Hole Pegboard (9HPB) and 8-metre Timed Walk (8mTW) Tests will be performed, blood will be taken to confirm the genetic diagnosis of FA and a series of questionnaires will be filled out.

### **What are the possible benefits?**

It is hoped that by participating in this study and as a result having patient data stored on the registry, it will allow patients to be informed promptly as to any relevant new research trials or projects that may be commencing which they may be eligible to participate in. This registry will be a large European data set, which will allow access to a great number of FA specialists when potentially recruiting to new trials.

**If you would like to participate in this study or know of any individuals who may be interested, and would like some more information, please don't hesitate to get in touch:**

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