

Update your FARA Patient Registry Account Today!

The Friedreich's Ataxia Research Alliance (FARA) patient registry is the primary resource for recruiting individuals with FA for clinical research studies and trials. The Patient Registry is also an important source of information about number of individuals with FA, average age of diagnosis, severity of FA, etc... questions that we get asked by scientists, pharma companies, and government agencies. The National Institutes of Health, Office of Rare Diseases, recently published common data elements for rare disease registries as way to help harmonize data collected across disease specific registries. FARA has updated the Patient Registry so that we are capturing these suggested common data elements and so that we are better prepared to meet the need of researchers planning and conducting clinical research in FA.

The data in our registry is only useful if it is accurate!

We would appreciate your help in answering the new questions and updating any existing information that has changed. ***This should only take 10 minutes as all of the original data is still in the registry.***

The new questions include adding a secondary contact person, demographic questions (ethnicity, education, health insurance), a few additional questions about your FA diagnosis, symptoms and quality of life and questions about participation in research.

Instructions: 1. Login to your registry account. 2. Re-confirm your consent to participate in the registry. 3. Once you arrive at your confirmation page, go through each section and be sure to answer all of the questions. 4. Once you have updated and answered the questions in all the sections please select "Confirm".

Note: You may get a message pop-up on the screen that says that a patient with your name and date of birth already exists and you will be asked if you want to cancel, make changes or continue. Select Continue!

The FARA Patient Registry is the primary recruitment tool for many researchers. These new questions will aid researchers in their work towards a better understanding of Friedreich's Ataxia and planning and designing studies.

If you are not currently registered, we invite you to join.

Just a reminder, your individual/personal information is not supplied to a third party or "sold". FARA only shares aggregate or anonymized data from the registry and all communications about study recruitments or notices are sent directly by FARA.

If you have any questions or difficulties with this process, or have forgotten your login or password, please contact us at FARA_Patient_Registry@curefa.org.