



Friedreich's
Ataxia
Research
Alliance



Friedreich's Ataxia Global
Patient Registry

The **Friedreich's Ataxia Global Patient Registry** (FAGPR) was launched in November 2019. The FAGPR has been developed by global charities supporting people with FA, including Ataxia UK, to be the international registry for FA research.

What is the FA Global Patient Registry?

Ataxia UK has a patient registry, mostly containing contact details for patients in the UK. Similarly, the US charity FARA has had a patient registry for several years, which has collected data from over 3,700 patients. These registries have been used to recruit for clinical trials and research studies. Companies developing treatments for FA often tell us that the ability to quickly identify and contact eligible patients for studies is one of the reasons that they became interested in developing treatments for FA.

Global partners have now come together to build a *new* international registry - the FA Global Patient Registry (FAGPR). This is a global effort of patient groups around the world to work together and pool information in one place making it a much more powerful resource for research. The new registry platform will allow for collection of more comprehensive information from registrants around the world, including medical history, use of assistive devices and quality of life, and will help promote global clinical trials. Over time, the registry questions will be available in multiple languages and will be accessible from multiple platforms (computer, phone, tablet etc.).

Why is a The FA Global Patient Registry so important?

One of the most important functions of the registry is to document the worldwide prevalence of FA. Understanding prevalence influences how FA communities in different countries can form collaborations for disease education and build expertise for FA medical management.

Additionally, when researchers are developing new drugs, they need to understand the disease in question, and the experiences of the patients. In order to run clinical trials, they need to be able to find patients who are willing to be a part of those trials. The newly developed FA Global Patient Registry has been built to help collect information about FA directly from patients, and to help match patients with studies that they might be interested in.

How do I register?

To register and to read more about the registry go to: www.fapatientregistry.org

Head of Research Julie Greenfield says 'We are very pleased to have joined forces with charities worldwide to develop and run the FA Global registry. Ataxia UK has a lead role, together with FARA, in taking on the responsibility for the continued support of the Registry and having an active role in its governance. We hope many people with FA around the world will join and that it will be a very useful resource for researchers. Please note that joining the FA Global Patient Registry is not a replacement for joining as a Friend of Ataxia UK. To receive communications and support from Ataxia UK it is useful to join as a Friend'.