

New Year's Resolution: Join the FA Global Patient Registry!

Dear FA community:

The drug development pipeline is closing in on a treatment for Friedreich's Ataxia. Patients can accelerate the process by being part of the Friedreich's Ataxia Global Patient Registry. Being part of the registry is a great opportunity to keep updated on what is happening and a choice to possibly participate in clinical trials. It is very important that all FA patients are represented in the patient registry.

Why is a patient registry vital to advancing knowledge about Friedreich's ataxia?

When pharmaceutical companies begin the journey of developing a drug for FA, one of the first questions asked is "Where are FA patients located around the world?" The answer to this question is important because:

Pharmaceutical companies will need to plan for clinical trials and eventual drug distribution and will need to be aware of regulatory processes in each country where FA patients are treated.

Pharmaceutical companies will need to plan for physician education about drug availability in any country where FA patients are being diagnosed and treated.

There are an estimated 15,000 individuals affected with FA worldwide. The current patient registry includes ~3,500 registrants. Therefore, the registry is missing ~11,500 of FA patients globally. Immediate access to contacting as many FA patients as possible about upcoming clinical trials avoids delays in the drug development process.

What does the patient registry not do?

Patient registry information is never used for fundraising campaigns.

Patient registry information is never shared with researchers and pharmaceutical companies without review of the scientific protocol behind the request for data. Data shared with researchers does not contain individual personal patient information until *after you consent* to a research study or clinical trial.

We need you in our fight for treatments and cure. Every patient counts. Please, join the FA Global Registry here: <https://curefa.net/registry/>. {If you have already joined the registry, please confirm your contact and clinical information.}