



Friedreich's Ataxia Research Alliance Future Donor Information Form

If you are interested in donating your tissues (at the time of surgery) or organs (upon death) for FA research we ask you to complete the form below so that we can help facilitate this important contribution to research.

We will be asking you to share your personal information (name, address, phone, email as well as FA and medical history) along with contact information for a secondary person who would be your next of kin or someone with power of attorney to make medical decisions or provide consent on your behalf if you are not able.

We will need to share your information with members of the FARA staff, researchers, physicians and third-party partners who facilitate the collection and storage of organ and tissue donation and storage.

We will not share your personal information beyond those who need this information to facilitate tissue donation.

If you change your mind about tissue donation, you may contact us at tissuedonation@curefa.org and notify us in writing that you would your name and information withdrawn from consideration of tissue donation.

Please fill out and return a copy of the signed form to FARA at tissuedonation@curefa.org or mail to:
FARA
533 W Uwchlan Ave.
Downingtown, PA 19335

I am interested in a future donation of my body tissues for research in Friedreich's Ataxia (FA).

Donor's Contact Information:

Last Name: _____

First Name: _____

Street Address: _____

City: _____ State: _____ Zip code: _____

Phone Number: _____ Cell Phone Number: _____

Email Address: _____ Date of Birth: _____

Questions related to your FA diagnosis

Age when FA symptoms began? _____

Age when you were diagnosed? _____

Do you have confirmation of Friedreich's ataxia performed by a Genetic Test that includes a Friedreich's Ataxia Repeat Expansion Analysis? Yes No

If you have a copy of the report and can forward it as a separate attachment, then you don't need to answer the next two questions.

Laboratory and Test result date: _____

Repeat lengths: Allele 1: _____ Allele 2: _____

Any other mutations (deletions, point mutations, etc.) in frataxin gene: _____

Who is your neurologist or where do you get clinical care for your FA — name and where you see them? (e.g., Dr. David Lynch, Children's Hospital of Philadelphia)

If you have you been seen at a Friedreich's Ataxia Global Clinical Consortium site, which one?

What symptoms of FA have you had?

loss of coordination (ataxia) in the arms
and legs
fatigue - energy deprivation
muscle loss
vision impairment
hearing loss

slurred speech
aggressive scoliosis (curvature of the spine)
diabetes mellitus
If diabetes, insulin-dependent
hypertrophic cardiomyopathy
arrhythmias

Do you have other medical conditions (not related to FA), for example any diagnoses of cancer, other neurological conditions, etc.?

Please help us understand your current health status related to tissue donation.

Good health, no urgent issues, wanting to set up tissue donation for some time in the future

My health is declining but no urgent issues, wanting to set up tissue donation in the event my health declines further in the next few months to year

My health is poor and I am near end of life

Have you selected a funeral home? Yes No

If so, what is the name, address, and phone number of the funeral home?

Secondary Contact Information (this person would be considered next of kin)

Last Name: _____

First Name: _____

Street Address: _____

City: _____ State: _____ Zip code: _____

Phone Number: _____ Cell Phone Number: _____

Email Address: _____ Relationship: _____

Does this person know about your interest in donating your tissues for FA research? Yes No

I give permission to the Friedreich's Ataxia Research Alliance (FARA) to share my personal information, shared above and attached, with FARA staff, researchers, physicians or other partners who help facilitate donation of tissues for research on my behalf. I agree that such researchers or partners can contact me regarding tissue donation. Electronic signature accepted.

Signature: _____ Date: _____

If you have any questions or choose to withdraw from tissue donation program, please contact FARA by calling (484) 879-6160 or email tissuedonation@curefa.org