

# Brain Tissue Donation for Ataxia Research

Thank you so much for considering this invaluable contribution. Your donation becomes a gift of knowledge that will contribute to the better understanding of Ataxia and, hopefully, a cure. The examination of diseased tissues by a trained pathologist remains the gold standard of diagnosis in addition to research scientists gaining a better understanding of the disease.

The National Ataxia Foundation (NAF) understands how difficult yet important this type of donation is, and we want to provide as much assistance as we can in helping you prepare for this contribution. Many of the documents that need to be completed are available before the time of death. Please do not hesitate to contact the National Ataxia Foundation at the phone numbers or email addresses listed below if you have any questions.

## How do I donate my brain tissue for Ataxia Research?

Pre-planning is essential since rapid recovery of the brain is very important. We highly encourage you to complete a Healthcare Directive to inform your loved ones, doctors, caregivers (e.g., nursing home staff, home care, hospice), funeral director, your attorney and NAF of your desire to donate your brain tissue upon death. At least one person should be designated to call **877.GoAtaxia [877.462.8294]** as soon as death appears imminent or has occurred. This answering service will notify NAF, and you will be contacted as soon as possible. NAF, along with our academic partner, will work with your family members, funeral director, hospital, or nursing home staff to arrange for the transfer of the body to an appropriate location and the tissue recovery will take place.

## Does the donor family incur any expense for the brain donation?

No. There is no financial cost to the family for the brain tissue donation. The donor family is responsible for regular funeral/mortuary or cremation expenses, or an official autopsy, if requested, to determine cause of death.

## When does NAF need to be notified of the death?

Timely recovery is a very important issue. An arrangement will be made with a pathologist to facilitate the recovery ideally within 6 hours, but no longer than 24 hours after death. Tissue donation does not disrupt the timing and viewing for most traditional remembrance services and still allows for open casket if so desired.

## Is the body transported to the National Ataxia Foundation office?

No. Recovery of tissue is performed at your local hospital, funeral home, or other designated institute. The brain tissue is then shipped to NAF's academic partner's laboratory.

## What happens to the body after the donation is made?

The body will be delivered to the funeral home or wherever the family chooses.

## What happens to the donated tissue?

The tissue will be processed and stored in a scientific lab. Notification of the availability of tissue for research will be sent to approved Ataxia researchers. Your gift may benefit dozens of different Ataxia research studies. Your identity and your family's identity will remain anonymous to the researchers.

General Information about Brain Tissue Donation

763.231.2750 | 763.231.2742

[mary@ataxia.org](mailto:mary@ataxia.org) | [sue@ataxia.org](mailto:sue@ataxia.org)

NAF General Office 763.553.0020

Immediate Response Needed for Brain Tissue Donation

877.GoAtaxia [877.462.8294]